FEMALE CANCER:
The Vital Role of Self Perceived Beauty in the Healing Process
A Study in Breast Reconstruction

Report of Findings
Nashville, Tennessee

By: Tamarin Lindenberg

Healthcare in Transition, LLC
The work of Dr. Pat Maxwell, through his pioneering innovations, and, often, the direct artistry of his hands, has redefined the future of women facing breast cancer... Each voice contained within these pages echoes the sound of hope--- so far removed from hollow despair, once the only sound in the room--- he is the inspiration behind this study, but, far more, he is the force that drove us forward to a life that left the reminders of cancer behind....

For Pat Maxwell....we call you healer, surgeon, blessing, innovator, physician, artist... we call you friend....
countless contributions made this study possible.... voices of the women who candidly shared their deepest views on subjects rarely discussed gave it meaning.... those who make up the CALIEB Dream Team gave it breadth.... artists, with their powerful interpretations, offered new language.....

time given freely by professionals from every walk made this a true collaboration....

homes were shared that made the journey across the US possible.....
meals were shared that made the long nights on the road bearable.....
hearts were shared that made it all worthwhile....

to each and every one of you who are so intricately woven within these pages, words will never be enough to thank you...
but making a difference will....
Dr. Pat Maxwell

Dr. Pat Maxwell, renowned surgeon, educator and innovator whose life’s work has greatly changed the post-operative results of women facing breast reconstruction. His innovations have changed the very texture and style of implants, while his surgical techniques have advanced the visual outcome of breast reconstruction to the level of breast augmentation. His dedication to the education of new surgeons has created broad reaching access to his innovations in breast reconstruction and, as a result, has offered many women the opportunity to move past cancer with renewed confidence.

Dr. Maxwell is nationally and internationally renowned for his achievements and advances in breast and aesthetic surgery. Hailed as a visionary for his innovations and surgical artistry, Dr. Maxwell strives to provide his patients with superior-quality outcomes that combine the latest surgical advances with personal insight from his years of experience helping a wide range of patients achieve their goals.

A gifted childhood artist and university student of architecture, Dr. Maxwell realized early on in his career that he wanted to enhance patients' lives by applying his innate creative talents through surgical procedures that provide a highly sophisticated approach to beauty, balance, and overall aesthetic form. He is a graduate of Vanderbilt University and Vanderbilt University School of Medicine, and received extensive surgical training through general and plastic surgery residencies at the renowned Johns Hopkins Hospital in Baltimore, Maryland.

While a resident at Johns Hopkins, Dr. Maxwell was impacted by the emotional and physical consequences of the radical mastectomy procedure, then performed on women with breast cancer. These experiences led him to research and develop operative procedures and devices focusing on the breast area. He was one of the founding pioneers of microsurgery and the field of breast reconstruction, both as a patient advocate as well as innovator of various "flap" procedures. He invented the textured tissue expander in 1986; this has become the main device/technique used world-wide for breast reconstruction over the last 20 years.

He furthered the aesthetic outcome of breast reconstruction over the last 20 years by working with Allergan to create breast implants and with Allergan developed the Natrelle™ Collection of silicone-gel breast implants including the 410 Matrix of "Form Stable," "Gummy Bear" or "Tear Drop" breast implants.

In 1990, Dr. Maxwell founded the Baptist Hospital Institute for Aesthetic and Reconstructive Surgery in Nashville, Tennessee, which The New York Times called "the first and foremost facility of its kind in the United States," and which W Magazine ranked as one of the world's Top...
10 cosmetic surgery practices. In 2008, Dr. Maxwell created MAXWELL AESTHETICS a private clinic housing a state of the art surgical center; here, Dr. Maxwell sees his geographically broad-based patient clientele.

Dr. Maxwell has authored over 100 scientific articles and lectured and performed live surgical demonstrations in over 20 countries around the world. He holds ten US patents (with seven more pending) pertaining to medical devices. He has contributed not only to designing the Natrelle™ Collection and the (style 410 Matrix) Tear-Drop or "Gummy Bear" breast implants from Allergan, but founded and chairs the Allergan Academy, the international educational forum, which educates surgeons on the use of these devices and other aesthetic surgical procedures.

While Dr. Maxwell has been included in virtually every "Best Doctor" and "Best Plastic Surgeon" list compiled in the last two decades, perhaps more importantly, he has received most of the major awards in plastic surgery that can be bestowed by his plastic surgical peers. He has been awarded the James Barrett Brown Award (by the American Society of Aesthetic Plastic Surgery), the Robert Ivy Award (by the American Society of Plastic Surgeons), the Walter Scott Brown Award (3 times, by the American Society of Aesthetic Plastic Surgery), and the Chul Song Award (by the American Society of Aesthetic Plastic Surgery).

His most recent awards include the Clinician of the Year Award by the American Association of Plastic Surgeons in 2009, for his "significant clinical achievements, long experience and results of treatment (in aesthetic and reconstructive surgery)." In 2008, he received the U.S. Congressional Recognition of Merit for "his visionary contributions to plastic and reconstructive surgery, service to others, and revolutionary developments impacting survivors of breast cancer." And in 2005, he received the Presidential Award from the American Society of Plastic Surgeons for "excellence as an educator and innovator bringing art and science to a new level for the specialty."

Despite his numerous awards, Dr. Maxwell's primary commitment is to the safety, personal care, and individualized, superior surgical outcomes he strives for in his Nashville cosmetic plastic surgery practice.

Dr. Maxwell’s extensive Curriculum Vitae (CV) can be viewed under Addendum A.
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Prologue

“... May of ’09 I had mastectomy of the right breast and then I was referred to a plastic surgeon there at (redacted-major university hospital system) for reconstruction, and he inserted a tissue expander... I was kinda weary about it because it was just two fingers below my collar bone and the tissue expander was way up here and my natural breast is not. And I kept asking him, ‘Is it going to be that high?’... he says, ‘Oh it’ll drop.’ And so throughout the whole process of having the tissue expansion I was kinda concerned because that doctor never really talked to me, never really asked me what outcome am I expecting... what type of implant he was gonna use, never... really never said anything and I kept thinking, ‘Well, it’s (redacted-major university hospital system), so he’s got to know what he’s doing, and he was referred by the breast surgeon so he must be good.’

In July of 2010, I went in to have the tissue expander removed and the implant put in... he put in a round implant and it was way up here under my collar bone... at the time he did a reduction on the left breast, and they obviously were not even close to similar, and he did not put on a nipple or anything, he said that I could just come back in later and have it tattooed on... that just didn’t appeal to me at all and I remember being depressed ‘cause I was thinking I was gonna have to go for the rest of my life with one breast up and one breast down... and he never... he never offered or suggested that maybe we can put the implants on the other side to try to even ‘em out...

... Whenever I would wear a bra, I would have to put something in the bra to fill out the bra on the right side because the breast was way up here... it just never filled out and I remember going back to him and for the final, hoping for him to relieve me, and I remember being so depressed and he looked at me and he says, ‘You hate it, don’t you?’ And I said, ‘I do; I hate it.’ And he says, ‘There’s really nothing we can do about it,’ he said, ‘one thing we can do is we can take a latissimus muscle’ -- or whatever he called it -- ‘from your back and tunnel it under your skin and try to fill out your bra like that...’

... Well I’d been doing some research online, and from what I’d read, a lot of people had had trouble with their backs after that, and the recovery time was quite an extended amount of time and there was no guarantee on anything like that... I still did not like the roundness... it didn’t look natural so I was always careful whenever I was leaning over... would put my hand up here because I just felt like I looked terrible and the memory bothers me even now. I just... I just felt terrible and (crying) sorry... Well, Dr. Maxwell... he solved it for me (crying)...

I remember looking online trying to figure out what my options were and I saw his website and really got excited about it... I saw his 4-D imaging or whatever it’s called... Precision Light... And I saw before and after shots, and some pictures that looked kinda like me... I thought, ‘I wish I could be like that...’ I read where he didn’t take insurance and so I was really... I was even more depressed because I was thinking the only alternative I had was to go back to that same plastic surgeon and have him do the muscle thing and I really didn’t want to do that...

My sister lives in North Carolina and worked at Duke Medical Center and she knew a doctor, Pat Whitworth, and so she called him and she told him about my situation and he suggested Dr. Maxwell... I thought, ‘this is amazing, because that’s who I’d want to go to,’ but I thought, ‘I really can’t do that because my insurance would not cover it and I don’t think I’d have the money to pay
for the rest of it...’ I went to another plastic surgeon for a second opinion and he wanted to know ahead of time who my plastic surgeon was and I told him, and when I came in and he looked and he said, ‘No, I agree with your plastic surgeon; there’s nothing else that we can do, that’s as good as it gets.’ To be honest with you, I felt like I wish I’d never had anything done... I’d just rather have worn the prostheses ‘cause at least they balanced out...

... I remember coming out of his office and I was sitting in my car and I just felt terrible and I pulled out my phone, I checked my phone and the voicemail was from Dr. Maxwell’s office, so I called it and they said they wanted me to come in for an appointment... So I came in and he showed me the Gummy Bear 410... He showed me that, and he showed me the round one like I had, and there’s just no comparison... I wanted to look natural and I was just really excited about that.

... It felt natural in shape, but all the time I was sitting there thinking, and I was talking to him, I was thinking, ‘This is really great, and you showed me all these things that I want, but I know that I can’t afford that.’... Anyway, we went through the whole process of talking to him... and when I came in to talk to the lady about how much it was gonna cost and everything, she said that Dr. Maxwell had said that he would take whatever my insurance would pay and that I wouldn’t have to pay anything else than that... That was great (crying) sorry (crying harder). I’m sorry... I just didn’t want to live out my life so depressed... It was affecting my school work where I teach because it was affecting my whole life and it’s not like... I’m an exhibitionist and I’m gonna go around showing off, but it affected me... So whenever they said that he would do it, I was... I was overwhelmed...

... I thought I was gonna have to look like that forever and I remember going to surgery and he put a small implant under the left one and he gave me this one and... I just can’t explain it, I feel complete, I feel natural...

I’m not a beautiful outward person but I feel pretty now (crying)... I had a hysterectomy back in December and the doctor gave me a morphine drip, my husband was sitting in the hospital room there and, because I’ve had lymph nodes removed, I’m not supposed to have blood pressure or IV’s or anything on my right arm, I remember one of the nurses came and she wanted to take my blood pressure and I said, ‘You can’t do it on the right arm, has to be on the left.’ She said, ‘Why?’ I said ‘because I’ve had mastectomy’, and she says, ‘Really? But you look so natural.’

... I said, ‘I know’...”
Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process
Introduction

This study presents the female voice in an exploration of breast reconstruction and the actual, as well as projected, impact an optimal visual outcome has on body confidence, sexuality and the ability to move forward, post surgically. A mixed population was a key component of the study design. Woven throughout are the intimate thoughts of women, produced by formal interviews and informal polls, offering a daring revelation of the critical role self perceived beauty plays in the life of a woman.

**Group One** is comprised of women who have faced a diagnosis of breast cancer, or have been diagnosed with a high risk for the same. Their responses capture actual experiences and subsequent insights relative to current treatment and communication models deployed by physicians. In addition, they offer a candid view of the patient’s psychological adaptation process to body alteration as the result of a cancer, or high risk, diagnosis.

**Group Two** is comprised of women who have *not* faced a diagnosis of breast cancer, nor have a known high risk for the disease. The responses presented by this group represent their *projected* view of the impact breast reconstruction would have on their quality of life.

Since Group Two represents a great majority of women in the general population, the inclusion of their voices offers what is likely the view of many women immediately prior to diagnosis. Statistically speaking, a significant percentage of women in Group Two will be reclassified to Group One at some point in their lifetime.

The purpose of this study is to advance the understanding of patient needs among the various specialties and disciplines involved in treatment from diagnosis to post reconstruction. In addition, this study seeks to present findings that will educate women of their options when seeking the highest standard in visual outcomes when undergoing breast reconstruction.

**Section One** represents the voices of female patients as they explore the relationship between their personal definition of beauty and their overall wellbeing after breast reconstruction. A mixed methodology was utilized in this section for the purpose of capturing both qualitative and quantitative findings.

**Section Two** represents the voices of women who have never experienced breast reconstruction and explores their empathetic exploration of how they believe they would respond to a diagnosis leading to reconstruction. A key component of Section Two is the respondent’s projection of the impact breast reconstruction might have on their personal definition of beauty. A mixed methodology was utilized in this section to capture both qualitative and quantitative findings. These findings are presented in **Section Two A**.

The coding process undertaken in Section Two A revealed intrinsic value in the interactive dialogue that took place between the interviewer and respondents as topics were explored in
These findings are presented in **Section Two A**. This section offers the reader a unique insight into a psychological exploration of the female relationship with beauty.

**Section Two B** presents the intricate relationship between women, personal aesthetic satisfaction and quality of life. It explores the impact this dynamic has on treatment options and ensuing psychological satisfaction, and the key role multi-specialty physicians play in affecting quality of life decisions. This section is presented in a dialogue format as the interaction between the interviewer and interviewees reveals a candid perspective of the female view of beauty and the role it plays in health, vitality and sexual intimacy.

Respondents were comprised of women from the Deep South, Midwest, East Coast, West Coast, and our Nation’s capital. The respondents were diverse in geographical location, education, ethnicity, exposure to the healthcare system, and in their own individual definition of female beauty. They were tall, small, thin, curvy, stylish, plain, of low to high income, unemployed, professionally accomplished, full time students, recognized healthcare leaders, homemakers, and professors. In every way, this report seeks to reflect a composite view of the quality of life value women place on satisfaction with their visual appearance.

**Section Three**, utilizing transcription provided by Allergan, presents the views of well-known surgeons as they explore the need to increase awareness among women of advanced reconstruction techniques. Permission to recode the original transcript for themes relative to this study provided an additional and valuable view from the surgeon’s perspective. Sincere appreciation is extended to Allergan for the use of the original transcript.

**Formal Interviews and Subsequent Poll**

The first 35 interviews were between 1.5 - 2 hours in length, held in one-on-one, face-to-face sessions, recorded, transcribed and coded according to themes set forth in the study design. The findings are presented in this report.

At various intervals over 2011-2013, over 100 respondents, spanning the US, were polled to respond to two key questions: 1) Have you ever heard of a nipple-sparing mastectomy? and, 2) What impact do you think an optimal visual outcome in breast reconstruction would have on your overall healing process, post cancer? These two questions were asked verbally, and were purposefully posed to women representing a diverse range of educational backgrounds, ethnicity, income levels and geographical locations. The results were overwhelmingly consistent with approximately 98% of respondents expressing no knowledge of nipple-sparing mastectomy techniques, and 100% placing a value of 8-10 on the importance of an optimal visual outcome on the overall healing process.

The informal poll produced information of such value that a more formal process was undertaken in the spring of 2013 to determine if such consistency in responses would continue. This process is a simple cross nation survey in which every state is represented by one woman, who asks the following two questions of 15 women in her state. In some states, the interviewer represents more than 1 state.
The questions are: 1) Have you ever heard of a nipple-sparing mastectomy? and 2) How important do you think an optimal visual outcome in breast reconstruction would be on the overall healing process, post cancer, on a scale of 1 to 10?

Each interviewer is asked to present the above questions to 15 women, per assigned state. The state-by-state selection criteria for the respondents will include five women of non-Caucasian ethnicity, an even mix of single and married individuals, respondents representing major cities within the state, as well as smaller outlying areas, and exclusion of groups who regularly interfaced. An additional criterion includes a range of educational achievement spanning high school to graduate level degrees; four respondents are to include healthcare professionals, either as service providers or administrative support.

Age range criteria, per state, for the respondents is as follows: three respondents in age range 21-30; three respondents in age range 31-40; three respondents in age range 41-50; three respondents in age range 51-60 and three respondents in age range 60+. In total, this will represent 750 responses across the United States providing a statistically significant respondent base.

This is the first phase of a multi-phase study that will provide much deeper insight into the psychology of beauty and its impact on the healing process.

**Principal Investigator - Tamarin Lindenberg**

“My broad mission is to challenge the biases that affect solutions offered to women facing female cancer, and to save lives, both figuratively and literally. I have been blessed beyond measure in my own journey and my heartfelt goal is to show that a woman CAN come through the devastating loss of all of her female organs and live whole -- emotionally and physically -- for that is the message I so wanted to hear at the point of my own diagnosis.” Tamarin Lindenberg

Tamarin Lindenberg, the Principal Investigator, has played the unique role of patient, researcher and spokesperson for women facing female cancer. She is an ovarian cancer survivor, a breast cancer (BRCA) patient and prophylactic mastectomy patient. Given her unique combination of skill, experience and perspective as a patient, respondents entered into levels of depth and exploration rarely experienced in the one-on-one interview process. Their candor and dedication to helping other
women made this not only an intellectual exploration, providing valuable data for continual advancement, but, their transparency and hopefulness in the future has made it truly a gift of love.

Tamarin is a Master level professional who founded and leads YarraDx, and Healthcare in Transition, LLC (HITI) organizations which serve a national client base. She has over 20 years of executive experience in start-ups and transitional management with an extensive track record in accelerated/focused growth, realignment, and innovative market positioning. She is highly regarded as a results oriented leader with strong interpersonal skills, and the ability to create, evaluate, analyze, and implement defined plans and objectives to achieve organizational goals.

She is recognized for the ability to balance strategy and execution and is well respected for her unique contributions to life science, behavioral research and patient advocacy.

She designed and led a Quality of Life research study with Dr. Pat Maxwell, internationally acclaimed surgeon and innovator, to show the impact optimal breast reconstruction has on a woman post cancer. Her work has gained recognition among some of the top leaders in healthcare. Tamarin has launched a nationwide awareness campaign in what she has named, "identity based cancers". These are cancers of the reproductive organs, including breasts, and apply to both genders. Tamarin has worked with key leaders in prostate cancer research, and, in 1996, created an intersection between behavioral and clinical research in prostate cancer that gained the recognition of leading minority health experts.

She has challenged the biases that affect solutions for women facing female cancers, and has been invited to explore many venues for educating practitioners in quality of life issues surrounding therapeutic options. She has raised awareness of the issues of reproductive cancers and its impact on a person emotionally and physically, and has fought to raise "life after expectations" for cancer survivors. CALIEB®, a patient advocacy program founded by Tamarin, is also being introduced and promoted to further educate practitioners and patients in an effort to raise the standard in women’s healthcare. Tamarin has established professional relationships with key executives in the business, investment, healthcare, life sciences, device, healthcare law, publishing, entertainment and political fronts, and is building support for CALIEB® through these relationships.

The diverse nature of her network lends power to her message and includes members of the top 100 national influencers in healthcare, key opinion leaders in medical device innovation, internationally recognized surgeons, global specialty pharmaceutical companies, lead scientists in reproductive and breast cancer research, venture capitalists, top 100 healthcare attorneys, lobbyists, entertainment celebrities and bestselling authors and researchers.

An ovarian cancer and breast reconstruction survivor, as well as an avid researcher, she holds a unique view and perspective on reproductive cancers, diagnostic methods and therapeutic interventions, research and physician viewpoints, as well as the viewpoints, fears and concerns of women.
Study Design

Initial Process

Over 100 patient files were reviewed in depth by Tamarin Lindenberg, Principal Investigator (PI), including a review of prior medical history, consultation notes, operating notes, and follow up care. Careful consideration was given to patient comments concerning the procedure, the follow up and the final result.

Patients with diverse experiences were selected as interviewees to ensure a range of responses. The PI held several exploratory sessions with patients to gather input for development of the study questions for patients. Exploratory sessions were also held with non-cancer patients to aide in the development of study questions for patients.

The interviews were conducted, on an individual basis, by the PI. The patient participant list was drawn from existing patients of Maxwell Aesthetics. A half day focus group was held with the nursing and support staff of Maxwell Aesthetics to explore their perception of the breast reconstruction patient journey. The potential interview list was presented to the staff to ensure diversity in range of patient experience and overall outcome.

Tamarin was introduced to the participants as “an independent third party, hired by Maxwell Aesthetics, to conduct a series of interviews to glean an understanding of their views of the impact of breast reconstruction on body confidence, sexuality and ability to move forward after cancer.” Participants were consented in writing, and on audio, and were informed interviews were recorded, stored at an offsite facility, and would be used to produce a blind Report of Findings, which would be presented to Maxwell Aesthetics.

Respondents were advised that comments presented in the final report, along with the statistical information gleaned, might be used for various educational purposes, included in a variety of publications, or used in various other ways to increase awareness of advanced reconstruction techniques.

Interview Structure

Interviews were allotted 1.5 - 2 hours each. Participants were asked a series of structured questions, but were invited to tell stories and add information of importance to them regardless of the format of the interview. This created an atmosphere of open dialogue, allowed richer content, and offered the opportunity to further explore areas of interest identified by the participant, but outside of the original survey design. This was extremely valuable in gaining insight into the current breast cancer patient’s environment and exploring ways to raise
awareness of the available options among the general public. The interviews were structured according to the survey questions initially developed.

Overall, participants were also invited to prioritize issues most important to them. Approximately 95% talked freely, while the remainder spoke specifically to the topics raised by the interviewer. The environment consistently created in the interviews was identified by the interviewer as one of “engagement and directed toward action.” This was accredited to the turbulent history of visual outcomes in breast reconstruction and an innate desire among the participants to ensure better options are available. The participants in both categories had seen, either first hand or via the internet, the average outcome in breast reconstruction. They described these outcomes as “horrifically scarred”, “asymmetrical”, “dented”, “unnatural”, and “deformed.”

Overall, respondents expressed an intense desire to see advances made in providing more aesthetically pleasing outcomes, and those who had undergone an advanced technique, as provided by Dr. Maxwell, adamantly expressed the need for all women to know that such outcomes are available.

As an added, but unintentional benefit, 90% of the participants gave unsolicited feedback regarding the interview process. This process was noted as “a chance to explore things never articulated”, and most felt it was a valuable step in their healing process.

**Benefits of the Process**

The interview process serves several purposes:

1) The interview time is designed to build relationships and express the interest of Maxwell Aesthetics, by the act of underwriting the process, in increasing its understanding of the patient experience and to discover methods to raise the standard for women facing breast reconstruction;

2) Trust is built through the effort of the interviewer to create an environment that encourages expression of ideas, experiences, and concerns as perceived by the participant. The interviewer maintains a neutral role and offers support to the participants’ articulation of their deepest thoughts and values. The results of the process were excellent, as defined by high levels of engagement, candor and independent feedback offered;

3) The data collected in this process provides valuable insight and highlights areas of concern, all of which propel us forward in improving the patient experience;

4) The data from recorded interviews is transcribed and coded for recurrent themes, and areas of high impact. The data is coded according to an agreed upon set of criteria; however, the transcriptions are retained by HITI and are available to process for a variety of themes at a later time should such prove useful;
5) A Report of Findings is presented that will categorize the data according to agreed upon criteria, provide direct supporting quotes from the participants, summarize findings in each category, and provide additional insights gleaned from the process;

6) A section containing actual dialogue between the PI and non-patients was added for additional insight and interest. As the PI is a cancer survivor and breast reconstruction patient, the data contained herein offers a unique dual perspective; and

7) The final section of this report contains direct quotes from surgeons as they explore the importance of ensuring the availability of advanced breast reconstruction techniques are made known to the public. This section is the result of coding a transcript of a panel discussion, provided by Allergan, in accordance with the direct themes of this study contained herein. The transcript is the property of Allergan, and the coding process was provided by HITI for the purpose of enhancing this study.

Additional Supporting Activities in Study Design

Multiple meetings were held at corporate offices of Allergan (CA) and LifeCell (NJ), to discuss the key findings of these interviews. Departments included were public relations, marketing, sales and product development. Responses to the work were intensely favorable with an expressed desire to continue the interviews in other population groups. Attempts to advance to next steps are ongoing.

Discussions were also held with a well-known cancer research center in Nashville. While the initial response indicated high interest in meeting the needs of women, as outlined in this study, attempts to follow up on the discussions with a call to action did not progress.

Discussions were also held with multiple key healthcare executives in Nashville regarding the need for a state of the art facility dedicated to female cancer. Responses included support of the value to patients, views that such a facility already existed, and the concern that such a facility would not meet the economic model of various hospital systems. Patient respondents, in Section One, did not feel that such a facility existed, and expressed strong support for the development of a facility ONLY in the event that it did not represent “another system that internally referred to participating physicians, without regard to patient needs.”

Discussions were held with a well-known national cancer hospital system regarding the needs of women, as outlined in this study. Discussions are ongoing and continue to develop.

Discussions were held with key health insurance executives in a meeting in Minnesota with a favorable first response. Further discussions will be explored.
Attendance at the Atlanta Breast Symposium two-day conference provided the opportunity to discuss the key findings of this interview process with international key opinion leaders and plastic surgeons with a focus in breast reconstruction. Responses from physicians included a desire for access to the Allergan 410, admiration of the high level of technical expertise evidenced in Dr. Maxwell’s consistent outcomes, interest in education to expand physician’s understanding of the patient’s view in breast reconstruction and interest in forming a coalition to ensure women were aware of their options when facing breast reconstruction.

The purpose and capacity of the Breast-Q was discussed with various hospital systems, researchers, and various physicians. The instrument design, which is an online, multiple choice, survey instrument, has successfully gathered a high volume of responses to specific questions confined to the answers available in the instrument. Though some sections may offer opportunity for open ended answers, the instrument is limited in this capacity. The design of the process followed under this report offers the respondent a face-to-face opportunity to explore their thoughts on a deeper level.

The Coding Process

As described above, participants were asked a series of structured questions, but were invited to add information of importance to them, regardless of the format of the interview. As previously stated, all interviews were transcribed and data pertaining to the categories originally designated are noted as comments throughout this document. The data contained within these sub-sections was ‘mined’ from hundreds of pages of recorded dialogue. Though the comments are reflected as quotes, they may have been edited in any event in which the respondent revealed their identity.

In Sections One and Two A, the comments are not a continuous flow of dialogue, but individually represent either a separate participant, or a pertinent thought presented on its own. Most respondents are represented one time, per question. In some cases, a full paragraph is presented as a quoted response. In these instances the thought process itself, as well as the direct answer to the question, was deemed to have value to the reader.

Section Two B presents full dialogue excerpts providing added insight not captured in the coding process. Section Three respondents are women who have neither experienced breast cancer nor fall in a high risk category.

The Findings are separated by tab and category to ensure ease in scanning through the material. Quotes were selected to build an understanding of the current culture surrounding breast reconstruction patients, and its challenges.

Independent coders, with experience in the coding process, but no relative knowledge of the subject matter, were used in an effort to preserve the objectivity of the findings. The overview, section summaries, final coding, added sections of interest and conclusion were written by the
Principal Investigator, Tamarin Lindenberg. Proofing and final edit were undertaken by the transcription team. Graphics and final layout were provided by an independent graphics team.

In the event there is a need to refer to the literal language, all recordings and original transcripts are retained by HITI on behalf of Maxwell Aesthetics and can be accessed.

Section Three comments were derived from a one hour panel discussion filmed in Miami. “Breast Reconstruction: Improving Patient Outcomes.” The final video program will be used on AllerganAcademy.com.

It is acknowledged that the specific comments in Section Three are the property of Allergan; however, insights presented are the result of the work of Healthcare in Transition, LLC.

The categories established for coding were developed by Tamarin Lindenberg, and may or may not reflect the original purpose as established by Allergan.

Summaries in this section are reflective of the comments of the respondents. The comments are reflected as quotes and have not been modified. Except for a few incidences, the respondents were unidentified in the original transcript.

The comments are not a continuous flow of dialogue, but individually represent either a separate participant, or a pertinent thought presented on its own. Most respondents are represented one time, per category. In some cases, a full paragraph is presented as a quoted response. In these instances, the thought process itself, as well as the direct answer to the question, was deemed to have value to the reader.

**Study Goals**

The goals of the patient interview process, as defined by Dr. Pat Maxwell and Tamarin Lindenberg, were to: 1) Gain deeper understanding of the depth of information given to candidates for breast reconstruction; 2) Determine, from the patient perspective, their referring physician’s knowledge of advanced reconstruction techniques; 3) Identify any bias(es) expressed by physicians towards any specific technique; and, 4) Explore the emotional impact breast reconstruction has on a patient’s body confidence, sexuality, and ability to move forward after cancer.

The goals of the non-patient interview process, as defined by Dr. Maxwell and Tamarin Lindenberg, were to: 1) Explore the general public’s overall knowledge of advanced reconstruction techniques; 2) Explore the views of women, in the general public, regarding the importance of the visual results of breast reconstruction; 3) Evaluate how public perception of breast reconstruction affects patient selection of treatment options in a breast cancer, or high risk, diagnosis.
Background of Participants and Its Relative Impact

Respondents represented in Section One, were those who had undergone breast reconstruction with Dr. Maxwell. Each had undergone a procedure that included the Allergan 410, Acellular Dermal Matrix (ADM) and fat grafting as a foundation; in some instances, a latissimus dorsi flap was also used. The patients had undergone prophylactic mastectomies with reconstruction, primary reconstruction, revisions, nipple-sparing, skin-sparing, unilateral and bilateral reconstruction. They represented age groups ranging from early 30’s to 60’s. This group of patients includes physicians, spouses of physicians, nurses, executives, homemakers, school teachers, and entertainment professionals. For the most part, they were reasonably well traveled, and had exposure to many environments outside of the southern region of the U.S.

Respondents represented in Section Two are comprised of women in the general population. Most know someone who has undergone breast reconstruction and all had either seen results first hand or viewed photos on the internet of average results; most had viewed the breast reconstruction photos on Dr. Maxwell’s website in preparation for the interview. They are located in the Southern Region, the District of Columbia, East Coast and California. They represent an age range from late 20’s to late 50’s, and are attorneys, physicians, executives, homemakers, pastors, and teachers. They are well traveled, and most had exposure to cultures outside of the U.S.

Emotional Response of the Participants

An emotional scale was monitored by the Principal Investigator with ratings of 1-10, 1 being unemotional or detached, and 10 representing a loss of emotional control. Respondents in the breast cancer/high risk patient category, on average, expressed an emotional demeanor consistent with scores of 5-7. This represented full engagement, tearfulness at critical points in storytelling, joy at “better than expected” outcomes, and deep pain when reliving an initial failed surgery or a lack of physician empathy at the point of diagnosis. One patient, scored at 9, expressed the heartache of her husband’s insensitive description of her breast reconstruction process. Another, scored at 8, expressed the excitement she felt when realizing her husband’s attraction for her post reconstruction body.

The respondents, overall, believed that information, concerning their options in breast reconstruction, was not made readily available to them, and their perception of the knowledge between physicians, upon whom they relied, varied widely. Most were scored at 7-8 when expressing dissatisfaction with the limited information provided to them by diagnosing physicians.

Respondents in the non-breast cancer/high risk category, on average, expressed an emotional demeanor consistent with scores of 5-7. This represented a range of responses from general interest to full engagement, tearfulness at critical points in storytelling, intensity at discussions
regarding expectations of full disclosure of options on the part of the physician, and deep empathy when recognizing that many women do not know their range of options when making critical decisions in breast reconstruction. One respondent was scored at a 10 when realizing that not all physicians made all options in breast reconstruction known to their patients.

Anger was repeatedly expressed by the non-patient group when discussing “physician led” decision making in breast reconstruction rather than “patient led” decision making; respondents, overall, placed a high demand on putting the choice of the method of breast reconstruction in the patient’s hands, with quality of life recognized as a number one priority. Over 70% of respondents scored at 8 when engaged in this part of the discussion.

Respondents in the non-patient category became highly engaged in discussions concerning the importance of providing patients with the full range of options available in breast reconstruction, and ensuring support of the woman in her decision of the option most suited to her expectations. The average score in this exploration was 7. They quickly defended a woman’s right to choose her course of treatment and unanimously expressed interest in contributing to efforts to ensure women understood their options at the time of diagnosis.

Overall, respondents in both groups placed the visual outcome on the same level of survival when asked to give it consideration.

Respondents described, in detail, the importance of beauty in self-confidence, overall productivity, and sexuality. They described a lack of self-perceived beauty as a trait that would greatly diminish their ability to fully engage in an emotional connection with a spouse or significant other.

**Expectations of the Women**

When questioned about expectations of a patient at the point of a breast cancer diagnosis, women expressed a desire for a very detailed plan designed to eradicate the disease and leave them physically whole. 100% of the participants expressed an expectation physicians would provide this plan without bias or practice serving motives. Values such as “integrity, honesty, a high regard for patient defined quality of life, open communication, up-to-date information, patient focused referrals, and a significant focus on teamwork” were reported, across the board, as central to the patient’s expectations of physicians at the point of diagnosis, and throughout treatment.

**Physician Biases**

Greater than 80% of the participants expressed a concern with physician biases surrounding the nipple-sparing technique. Respondents reported that diagnosing physicians, and breast and plastic surgeons, other than Drs. Maxwell and Whitworth, did not discuss the nipple-sparing
Patients expressed dissatisfaction regarding the limited information their oncologists offered in the area of breast reconstruction, and most patients felt their oncologists placed little value on this element of their treatment plan.

One patient, in a high risk category, reported her oncologist as advising her to “wait until you get breast cancer” rather than run the risk of the physical deformity and emotional devastation he associated with breast reconstruction. This patient later reported the joy expressed by this same physician when she returned to his office to show him the results of her prophylactic mastectomy and reconstruction using the nipple-sparing method, 410s, ADM and fat grafting procedure. She reported that he acknowledged a need for more information regarding the techniques available so he could better advise patients in the future.

Patient Discrimination

Respondents highlight two significant areas of perceived discrimination: 1) the preconceived ideas physicians may have about the importance of the visual outcome in breast reconstruction based on the patient’s age, assumed economic resources, marital status and overall physical appearance; and, 2) the reduced importance influencing physicians often place on female sexuality. Respondents often noted the value placed on preserving erectile function in men, post cancer, yet they did not feel a corresponding level of importance was placed on the preservation of visually appealing breasts after breast cancer. Respondents consistently expressed the view that their breasts were an equally important sexual organ and deserve the same level of care in visual preservation.

Unique Resource for Women Facing Female Cancer

CALIEB© www.CALIEB.com

CALIEB© was created in 2008 by Tamarin Lindenberg to assist women in their journey through female cancer. Its mission is to provide women with vital information to lead them through the many challenges, from early diagnostics to restoration after cancer.

Having led prostate cancer research initiatives, Tamarin had worked with men facing the fear of impotency, post cancer treatment. This was a significant driver behind many men's hesitancy to undergo aggressive treatment -- even when it was lifesaving—and she realized the same conundrum was experienced by women facing cancer of the female organs.
Recognizing the critical role self-defined beauty plays in a woman’s healing process after female cancer, CALIEB delivers a plan to address the after effects of cancer treatment and hormone suppression therapy. Boldly addressing the disparities between current treatment plans for male and female reproductive cancer, CALIEB closes the gap by offering women resources to preserve sexuality and self-confidence, post female cancer.

Following in the footsteps of Dr. Pat Maxwell’s lifelong team approach, CALIEB© developed a Dream Team of physicians, who are, together, able to deliver the complete restoration of a woman, post cancer. The physicians are all sub-specialists who, through shared skills, give a woman back a sense of complete wholeness after cancer.

The intent of CALIEB© is to change the perception of who a woman can be — post cancer — as the need for a role model is consistently expressed among all population groups. CALIEB© brings a unique concept that serves women with reproductive and breast cancer, or those in high risk categories.

Discussions are being held, ongoing, with various PR firms and media contacts regarding the patient advocacy program, CALIEB©. Upcoming interviews will assist in sharing information regarding this work with the general population.
The following represents actual email excerpts between a BRCA1 patient facing a prophylactic mastectomy, and physicians she sought to help her achieve an optimal visual outcome.

Physicians noted below are comprised of a major university breast surgeon considered a pioneer in nipple-sparing techniques, a recognized plastic surgeon in New York City, and a supporting plastic surgeon at the same university hospital. The plastic surgeon referenced in one physician’s email is a renowned thought leader in breast reconstruction.

The patient was a physically fit, 47 year old BRCA1 positive patient who had prior breast augmentation with incisions around the areola. She was determined to find a way to greatly reduce her risk for breast cancer while preserving a self-defined sense of beauty.

**Patient:** I have now compared these pictures to mine, and other websites after mastectomy…. what I seem to be pointing out that is most concerning to me, is the need to have a look that is tight…. Not loose in areas and uneven looking…. The roundness is something I can live with though I see that it is different from me…. What I do like about the photos in the link I sent you is that the breasts are tight in the pocket of skin….can that be achieved with me, while keeping my nipples in the right place?

I realize I have sent you a number of emails, and I apologize for the trouble, but this is a life changing decision for me, and it is very important to me to love the result....

Breast Surgeon (copy of original email): it is reasonable but i feel at this point it outweighs the true goal and mission i have for my patients.....cosmetic outcome is important but never guaranteed....our issue here is to cure you to the utmost possibility for you never having to face breast cancer.....discussing pictures and other such expectations takes away from our mission at (redacted a major university hospital).......

Breast Surgeon (copy of original email) : i am very sorry to tell you that at this point, i cannot in good conscience accept you as a patient.....i think that somehow through all of this, you have lost the first and most important concept that you are at high risk for developing a life threatening disease and so the first and i think only important issue is that you have all the breast tissue at risk removed.....as for the next step of reconstruction, nothing is guaranteed...your e-mails to my plastic surgeon seem to be most concerned about visual physical outcome....i know that we are actually quite excellent with our reconstructive results but if you feel comfortable with a non university based team on your side, then please continue your future care with them....
Patient: I am so devastated by this email, and hope you will reconsider. I have been working all weekend on getting ready for the surgery Monday that I need. I did not see any pictures when I was at your office and, of course, I need to understand the visual outcome in an elective surgery. I have been through so much and am trying to make the best decisions.

Plastic Surgeon (copy of original email): I AM OUT OF THE COUNTRY AND HAVE EXHAUSTED MY ABILITY TO MAKE YOU UNDERSTAND THAT WE ALL DO THINGS SLIGHTLY DIFFERENTLY. THERE IS NO RIGHT OR WRONG ANSWER FOR YOU BUT I BELIEVE THAT (redacted world renowned plastic surgeon at major university hospital) WILL DO AN EXCELLENT JOB AND WE ARE UNWILLING TO SPARE YOUR NIPPLES IN THIS SITUATION.

Radiologist (copy of original email): I understand what you want. I just don't know who can get you there.

(The patient went on to have an aggressive removal of all breast tissue with a nipple-sparing mastectomy in Dr. Maxwell’s hands. All of her tissue survived and there were no complications.)
**Artist:** Sophie Lindenberg, 16, watched her mother face a prophylactic removal of her breast tissue in an effort to eliminate her high risk for breast cancer. She witnessed the determination to undertake such a decision and retain the sense of femininity her mother felt would be vital to her life moving forward.

The journey began when Sophie was 12 and she was a dedicated participant—changing drains, recording volume, noting each detail of change and shape as her mother was given her life back.

When she presented this rendering she said, “I hope this won’t be offensive... it’s just you know I want to be a plastic surgeon, and I have watched you as you struggled to have what you believed in... Mom, it’s called, “Rage Sets in; Tears Swell”
SECTION I

Section One introduces direct quotes gleaned from interviews with patients who have undergone a mastectomy with breast reconstruction for therapeutic or prophylactic reasons. The patient’s view of the female perspective of the importance of self-defined beauty, and the struggle to retain such through female cancer is explored. The value optimal breast reconstruction plays in the overall healing process is brought to light, while the disparities within our current healthcare communication system are revealed.

Interviews

A. Patient Background

Sharing a variety of stories and circumstances, women reveal the many steps that led them to the decision to have breast reconstruction.

1. What were the circumstances that led up to your mastectomy/reconstruction decision?

“My sister was diagnosed with breast cancer when she was 36. And when I was 32 -- I was about to turn 32 -- I had just had my first child. And I decided to have the genetic testing done, and I tested positive for the BRCA2, and it just wasn't a decision after that. I mean, I knew that I wanted to be around forever to take care of my family, so that’s how I decided”

“They said, ‘I suggest that your options are, radiation and chemotherapy, without losing your breasts, that or mastectomy.’ So I thought for not too long, and thought if I can find a surgeon to work with me financially on the reconstruction, I’d rather choose the mastectomy than what I had seen and heard about chemo and radiation, and if you do radiation, it's really hard to do reconstruction after the fact, and I don’t know if my information was all informed, but I... that’s what I was rattling around…”

“... So I chose the mastectomy, ‘cause it had been good for my grandmother; she had lived to be 91. My mother was a long time breast cancer survivor, and I thought, well, where I was predisposed perhaps in the first place, maybe I'm predisposed that in the last place.”

“... fortunately, the breast surgeon, in his second lumpectomy, kept some other areas to see, if indeed, it was there, and he found it... and that probably helped saved my life... that’s when I finally agreed that I wasn’t gonna try a natural route, that it was too dangerous a risk, and I followed his recommendation and went with the mastectomy... but I do believe, in that process, I lost some of my contact with the breast surgeon because he recommended, from the beginning, the mastectomy... and, I kind of pressed for a second lumpectomy... if you don’t find it, if you didn’t find it in the first one and you don’t find it in this lump area, that I can possibly save my breasts? I wanted to do that if I could do it with some degree of safety, and I pressed him on that... he did do a second one... but when he did test another area and found it, he told me what he found and recommended that I follow his recommendation, that I do the full mastectomy... and, to some
degree, I hurt the relationship with the breast surgeon’s office and his staff... I think, eventually, it healed, but the fact that I delayed it, trying to figure out my options, I think it hurt it..."

“... immediately upon knowing that I needed a mastectomy, I made the decision that I wanted a double mastectomy, just for peace of mind... knowing that I didn’t want to have to go through that ten years later... I took chemotherapy with several women who ten years later went back with cancer in the other breast.”

“I knew... the sinking feeling was just there... They did the biopsies there, and the doctor called me about three or four days later and said, ‘we need to talk’, which I knew, so we talked.”

“It was summer of 2008, and felt a lump, or she did, I just did, and so, terribly concerned about it, that that’s not right. So, I freaked out, but... called the doctor and scheduled a mammogram... we were getting ready to go on vacation so I went on vacation, which I’m glad now that I did... anyway, we did scheduled a mammogram, had the mammogram... I knew very quickly there was something. I was so unconcerned that it was going to be anything wrong that it was my youngest son’s birthday and I took him with me thinking it was in and out, in about an hour. Left him with the nurses in the waiting room with his little Game boy, and really didn’t think about it. They came back and said they needed to take some more pictures or something. Then they took me to the ultrasound, they wanted me to wait and talk to the radiologist, so... we knew very quickly that it wasn’t... not all was well. So, and the very next day it was biopsied.”

“So I started having mammograms... when I was 25, and I was very open to that because I wanted to watch what was going on... that was good, for about ten years, and in the fall of the year I turned 40, I had a little calcification and then the doctor said... wait, probably did say ‘uh-oh’, ‘cause men were not... male doctor... not very sensitive to the language that they used with women, I don’t think, or patients maybe in general. I think patient care has changed a ton over time and I don’t... haven’t had a doctor say ‘uh-oh’ to me in quite a while, which is a good thing, but like okay, we’ve got to watch this...”

“When I went for the biopsy, I did it at a local hospital, and, again, I don’t think folks were terribly sensitive... I went for the biopsy, and it took the doctor a long time to put the needle, get the needle in the right spot, which was just a little bit traumatic to begin with, and then they put a cup over my breast like a Styrofoam cup over my breast and then they put the hospital gown on top, so I had this cup on my left breast poking out from a hospital gown and then they wheeled me back into like a waiting area for my surgery... it was just an unbelievably humiliating experience. Hopefully the hospitals aren’t doing women that way anymore either...”

“When I was diagnosed, originally my breast surgeon received the diagnosis and told me the following morning after the mastectomy and said the cancer had been there. She said she was going to the board to determine... the oncology board at the hospital... to determine what appropriate treatment should follow.”

“Since my mother, my grandmother, my aunt and then me had had it, my sister, she decided that maybe she needed to start doing something proactively. She’s a couple years older than me and she had several biopsies done because of nodules and none of them cancerous but she was afraid that something would come up. So she decided she was going to have prophylactic bilateral mastectomy also, and her doctor told her that there was no way she can have nipple-sparing because it just didn’t work. So anyway she had the mastectomy and the pathology report when it
came back indicated cancer and she had cancer at that point. She didn't have to do any radiation or chemotherapy or anything then but the cancer was there. And it was evidently she caught it so early that the MRI didn't even pick it up. So but her... I talked to her not too long ago and asked her... how she's been. Her outcome was not as good as mine. *(What are the major distinguishing differences...?)* Between her and myself? *(Yes.)* Of course I had the cohesive gel... my physique looks more natural than hers. She had saline implants. She had skin-sparing but she did not have nipple-sparing, so of course she had to go back... I think she's decided she doesn't want that. She just doesn't look as natural as I do. ... I compared it to mine but when he told her that he could not do nipple-sparing, when she did not have cancer at that point, because it just didn't work that just blew me away. Absolutely blew me away. And only reason why, and this is just my personal opinion, that he didn't do it was he didn't know how to do it.”

“It was done electively. I had a diagnosis of atypical ductile hyperplasia about nine months prior to the mastectomy. At that time, and with my family history of breast cancer... my mother died of breast cancer and my sister also was diagnosed with breast cancer when she was sixteen and with that information, I decided to go ahead and have mastectomies done.”

“In late 2005, I was diagnosed with breast cancer... in the spring, I had lumpectomies... 2, and finally a mastectomy. My left breast was done immediately after the mastectomy, a colleague of Dr. Maxwell did the expander... some months after that, I came back in for an implant to be put in. My breast was medium size C-cup but the non-implant side was much heavier. Of course the implants are very elastic and so it was very lopsided, very, very lopsided after. And the surgeon, who did the original work indicated, well we'll go back in and do some corrective work later on. I wasn't much for being cut on and dealt with in that way in the near future, and not by that physician.”

“Several years ago my sister-in-law had breast cancer and I saw what she was going through. She had a single mastectomy she went through chemotherapy and radiation and I asked myself then or thought, ‘what would I do if this ever happened to me’, of course never even thinking it would. But I thought at that moment in time that I would not have a mastectomy, I would not go through chemotherapy, I would not go through radiation because I saw what it was doing to her. When I was diagnosed with breast cancer, I had a lumpectomy and it was more so with the thought of ‘get this knot out of me’, never thinking it was cancer. Then when the test came back there was a cancer, I had absolutely no idea what to do, none. Nobody told me, nobody informed me of any decisions I sorta kinda had to go and find it on my own...”

“... I found a lump in my breast. I am one of nine women in my immediate family that has had breast cancer...”

“... I went straight to the... to where she referred me, just in town, to have my mammogram and the girl that did the mammogram, she said ‘there’s nothing here.’ I said, ‘No, she told you to do an ultrasound; do it.’ Then I had the ultrasound done, then the radiologist came in and said, ‘I need to refer you to Dr. Whitworth right away...’ I went to Dr. Whitworth, and he wanted to do a biopsy and I said, ‘go ahead and do the biopsy’, and he said, ‘yes, it looks like cancer, but we can’t confirm it until the lab comes back’, and then he wanted to send me to the oncologist, which was in the same Baptist building... I felt funny so I went and found my own oncologist... so I went to Vanderbilt and found out okay, what are my
options, what do I need to know, and, I went back to Dr. Whitworth and I said now, ‘I wanna approach this my way... give me my options, I wanna do it my way’...”

“Because we've had numerous breast opts, numerous aspirations, numerous all this other stuff. And the nurse practitioner felt something. It was kind of more lumpy than usual and she did an ultrasound on it. And then we did an aspiration... not an aspiration but it's a very wicked needle biopsy thing... but it's a fat needle that sucks it out... biopsy on this mask, which turned out to be a triple negative metaplastic breast cancer, which was 2 ½ sonometers large, which was impressive to me because I've had routine follow-ups and all this stuff and we never saw it. It didn't show on the mammogram. When we did the MRI it was big as... you could see it. I mean it was clearly big as a golf ball. But it was behind a fibroadenoma that had been biopsied in the past. And the only way it was felt was because it got bigger than the fibroadenoma that it was behind. And it was kind of lucky it was found I think at this point, which is why I was moderately pissed about the whole thing. You'd think something that big would've been seen somewhere, but it never showed on the mammogram. You go back and you look at the mammograms and it's never there.”

“... So had the biopsy and it was diagnosed. And I went to an oncologist, and with the surgeon and the oncologist. We talked about it and a mastectomy was what was determined to do because of the location. It was the upper outer quadrant of my right breast, and because of the size we determined to do a mastectomy.”

“... No one had ever given me that direction and it wasn’t something I was thinking about, nobody seemed concerned about it... So when I went back to him, he walked in, and looked around the door, and said, ‘You didn’t bring anyone with you?’ I went, ‘No’... ‘Cause I was thinking he’s there to check the dressing and to make sure everything’s healing right... and he said, ‘well, it's cancer.’ And that was how it was given to me; that was it...”

“... he said, ‘well, you can go into my office, if you want to, and talk about it...’ so I went in there and he said ‘well, we’ll start you on chemotherapy and we’ll start you on radiation...’ this is a general surgeon who was telling me this... Not maybe you need to see if you want to see a specialist because we don’t know about your family history and all this... So there was no information given to me... When I left his office I went back to my office and got on a computer and typed in the word irregular margins breast cancer and it came back that tumors with irregular margins can indicate breast cancer...”

2. **What were the reasons you chose breast reconstruction after a mastectomy?**
GRAPH #1: THERAPEUTIC OR PROPHYLACTIC MASTECTOMY

81% OF THE PATIENTS INTERVIEWED HAD UNDERGONE MASTECTOMY WITH BREAST RECONSTRUCTION AS THE RESULT OF BREAST CANCER.

“... My uncle, who’s a plastic surgeon, took a look at what had been done to my left breast and said, ‘boy that was a big...’ It’s a big incision and a lot was taken out and he said, ‘whatever you end up deciding, you’re probably going to want to have some reconstructive surgery anyway...’ then my other uncle was a radiologist and he said, ‘let’s watch it...’, then uncle... the plastic surgeon, said, ‘how can you watch something you can’t see...’ I think it was... it was that statement from Uncle Charlie who... but I mean if you have a favorite uncle, he’d probably was my favorite uncle...”

“... all that I saw was I am the only person out of the women in my family that have had cancer that elected for reconstruction.I knew that I did not want to not have reconstruction. I did not feel whole either. I wanted to have two breasts and that is the reason I went ahead and had it redone...”

“Emotionally, she was never the same. My step-father was not the most understanding and they ended up divorcing over it. She never felt whole again after that, but I mean the scarring and, like I said, they took muscle, it was just awful. They took everything. She could not lift her arms up...”

“... didn’t want to take the chance. And so I really opted for the mastectomy myself...”

“... My mother was diagnosed with breast cancer at age 29 and died at the age of 35. Three of her sisters were diagnosed in their 30’s. After the third sister was diagnosed, I was in my early 20’s. I had to... we did the genetic testing in our family, had the BRCA2 gene. I had been tried to talk into the surgery and had met surgeons three times. My first cousin and my grandmother both were diagnosed with breast cancer in 2010, the same side of the family, so I started doing research, thinking I needed to do something, and that’s how I found Dr. Maxwell, ’cause the surgeons I had spoken to in Memphis, I wasn’t happy with them or the results that my aunts had received with their reconstruction. So I was looking for something else.”
“... Dr. Maxwell saw me almost immediately, which was a really wonderful beginning to the reconstruction piece because I pretty much had decided that I just did not want this breast tissue hanging over my head for the rest of my life... (And this was 20 years ago?) Uh hm.”

“I just had one of them... Now, this doesn’t directly affect the plastic surgery part, but I got to tell you, after the removal, they removed some more lymph nodes too, and they were all clear, so as far as I was concerned, it was a surgical cure, as far as my surgeon was concerned, it was a surgical cure...”

“I had already, in my mind years ago, determined that if they ever found cancer, I was just gonna have it taken, rather than take an opportunity to have it come back again. And he did ask me, he said, ‘Do you want both breasts done?’ I said, ‘Yes.’ I said, ‘The set-up is already in the right breast... why wait for something that could happen again in three to six months?’”

B. Sources of Information Concerning Breast Reconstruction

Interviews revealed a wide disparity in information made available to women at the time of diagnosis. Most relied heavily on resources available online, yet all noted how limited those resources really were. Women were generally dissatisfied with the depth of information regarding breast reconstruction.

1. How did you become aware of the various methods of breast reconstruction?

Respondents candidly reflect on the various sources of information made available to them. They include online searches, diagnosing physicians, neighbors, family members and support groups. Throughout, women note the lack of a central resource providing comprehensive, objective information regarding their options.

“I got on the internet, and I figured out I had to have it... the different types, the implants, the tram flap, and the where they go in and take the muscle out of your back. My sister-in-law had had breast cancer and she had one breast removed and they took the muscle out her back and she was stage 0 and she still chose to have a mastectomy... they took it out of her back and it was very very invasive for her, for a long period of time because they had to take the muscle; I don’t understand why they couldn’t use her pec... Just getting the different types of information and the pros and cons of each one that the tram flap was much more invasive surgery originally, but it was your own tissue, you didn’t have foreign body... you didn’t have to worry about it leaking... because it was your own tissue but yet you had the necrosis factor, and a fellow teacher that was diagnosed with breast cancer six months prior to me, that’s what she had and she had that done at (redacted-major university hospital system) and almost her entire breast died. In fact she’s here now with Dr. Maxwell, she’s been down here getting fixed, trying to get fixed from that...”

“Definitely other people... I have a neighbor, who had just gone through it a year prior to mine, and she actually had the typical mastectomy, bilateral mastectomy without the nipple-sparing, so I could go and talk to her about it, and I actually got to see what it looked like. That was very helpful...”
“I was just back at square one but the nipple-sparing came about when I started thinking about doing the bilateral mastectomy. I just couldn’t handle the thought everything was coming back and I was spending time on the internet looking at chances of recurrence... I mean it was just taking up my life, but I did do a little bit of research and I had read about it before I went to Dr. Whitworth. I was very surprised and very pleased actually when he said that I was a candidate for the nipple-sparing and then he went about and told me more and more about it so just a little bit I’ve seen in research...”

“... when I went to see Dr. Whitworth, he immediately said this is what it is and we started on this course... So with the specialist, he actually started giving me information, as well as me doing all my own research. As far as my sister-in-law, she got the same thing I got; until I started taking things upon myself to do... no doctor was telling me much...”

“My breast surgeon was very good and yes. She said that she thought that it might be necessary to go back in and do more extensive surgery, although she wasn’t certain what she could do since she had removed the fascia on the chest wall and really was unable to go much deeper but thought that I would probably need additional therapy of some sort but she wasn’t certain what to do, and that was the reason she was taking it to the oncology department and the board meeting at the hospital to get that determination.”

“When my breast surgeon told me that no treatment was necessary by the board, I initially didn’t say anything because I wanted to hear enough information that I could decide what I thought was going to be the next step and so that I would have enough information that I could make my case for whatever I thought was necessary. And so I didn’t want to say anything without knowing what I was talking about. I felt that they were the experts; I was the patient. They had to know more than what I did. (Can you tell me what profession you are in?) I am an M.D.”

“I got my information over the phone, which wasn’t a bad way to do it but it would’ve been nice if somebody called you and said, ‘Hey...’ and I’m not faulting who’s the nurse practitioner because I like her. She's good. It's just... Hey, that first thing we tested was the fibroadenoma, but unfortunately the second thing was breast cancer, and so we needed to get an MRI and da-da-da-da and that’s it. And I'm like, bummer...”

“This was my first time through any of it. I had a gene question, but I have a gene question on anything. But this in particular was personal and very frightening when you first get such a diagnosis. And I was just bombarded with all sorts of fears and information and decisions I had to make. So every doctor or medical person I had to deal with, I had questions. And I went into his office for an interview before the surgery, before the mastectomy, and asked him some questions and we sat down and talked reasonably well. Then when I came back, I had additional questions and I ended up talking to his nurse and she went in and talked to him and so she brought me back into him with my additional questions. And he was like, you have more questions, it was like what other questions could you have? He didn’t say that, but that was his attitude. And so I asked my questions, and but after that, given that reaction as if I should not have any more questions and he had all sorts of credentials on the wall and had been doing it for years. But with that kind of attitude of... at my questions, I decided that’s not who I want to do my plastic surgery behind the mastectomy and that’s when I went and requested the surgeon to give me another recommendation and I ended up in Dr. Maxwell’s office...”
“... The approach made me uncomfortable. He was just... when I asked question... he wanted to use the saline implants and I just, I never felt comfortable with him. Everything was ‘Well, it’s so much better than it used to be.’ And I thought, ‘There’s got to be something better than what you’re describing to me.’ So, just to help me have an understanding of that experience, when he was saying ‘Well, it’s better than it used to be...’ his response was, it’s better than it used to be, not that we can meet your expectations?”

“Dr. Maxwell... He solved it for me...”

“... I went home and I had my next follow-up appointment with my breast surgeon in a week, and I was up until three and four o’clock in the morning. I was going over journal articles everywhere that I could find them online. I had a stack of over a foot high of journal articles that I was going over that I printed out because I really wanted to know what the best treatment was going to be. I wanted to know what the problems with any proposed treatment would be and what the benefits would be. I thought that was the only way to really know in my particular case what the best option was for me. Not what it might be for someone else but what was the best choice in my case, and I felt that I was the only one that could make that decision.”

“... I tried to walk a delicate line about being disrespectful or... or as if I know more than a doctor or someone in a field that I’m not in, but at the same time, especially in this case, I’m asking about me, my health, my life, of my appearance and I had questions... and I have questions now but they’ve... being here and with the staff and Dr. Maxwell, that has not been a problem and I’ve stayed and been very grateful that he took the case and he straightened out to a great degree what was left, what should not have been left...”

“And so, I contacted a few of those people. And my plan was to just go for ten days and stay in a surgery suite and kind of think and do the recovery thing, which would've been so much harder than staying right here. And then, when I found out that Dr. Maxwell was here -- and I did tons of research, almost trying to talk myself out of staying in Nashville because I thought, ‘Okay, this can’t really be the best choice because it's in Nashville.’ The best plastic surgeons and what TV tells you, they're in Los Angeles. And so, I think I did -- I just had to do lots of research and convince myself.”

“... there were some... frankly kind of scary procedures out there like the tram flap? Yes... I’m not sure that I would want to go that route. That wasn’t an option for me anyway. I didn’t have enough... I guess I didn’t have enough to do this, so I couldn’t do that anyway. It’s confusing. I meant the tram flap... I had been at one time a pretty avid tennis player and I was worried that... I felt that was really more invasive than I wanted to do or needed to do...”

“... From the internet I saw... I remember seeing, there was this one woman she posted a video of her breast reconstruction and she was talking about that muscle, latissimus dorsi... she talked about how painful it was and it had been a good deal of time since she had had the surgery, a year or two, and there’s a huge big scar across her back... I don’t care about scars... no one’s going to see my back anyway... I was just thinking about pain and she talked honestly about her pain and she still talked about she felt she was deformed even with that... she showed her breast and she didn’t look balanced out or anything and I remember thinking to myself, ‘why put yourself through that with that same doctor that same plastic surgeon who thinks that it looks okay as it is?’”
“... Dr. Maxwell took my case and showed me pictures of women that were very similar... similar that had nipple reconstruction and the implants so that I could see and then with the imaging... this is what you... what our hope is that you look like with the computer... I didn't get any of that at (redacted-major university hospital system). It was just cookie cutter, we'll do the tram flap and blah blah blah...”

“... with all the pictures he showed me, there were minimal scarring... I was concerned with the mastectomy but they had to go right across the center... my friend was proactive because by doing that, she prevented cancer. She prevented a lot of the things that... that I couldn't prevent. So I do have a line that goes across but they're very minimal, very minimal. A lot of that I think is technique... I've seen a lot that look like railroad tracks...”

“... Called my mom, and she called her brother who was a physician here in town, and he was a plastic surgeon and whatever doctors he knew back were all over the research about... and so I started reading and reading and reading and what I read about lobular carcinoma in situ is it was not the worst diagnosis that you could have, but I read that it was likely to be in the other breast...”

2. Did anyone discuss the possibility of a nipple-sparing mastectomy with you other than Drs. Whitworth and Maxwell?

*Time and again women speak to the importance of the nipple-sparing technique and its positive impact on the visual outcome. Despite increased satisfaction with the visual outcome, as reported by women after the nipple-sparing technique, few women were made aware of the option prior to their meeting with Dr. Maxwell and team.*

*Women, who believed they would have benefited from the technique, yet learned of it after a traditional procedure, were deeply saddened by the lack of knowledge shared with them at diagnosis.*

*Note to reader: For the ease of layout, we have omitted the consistent references to the names Dr. Maxwell and Dr. Whitworth in the quotes below. With the exception of one comment, all of the comments below refer to Drs. Maxwell and Whitworth as the only physicians who discussed the nipple-sparing technique in a positive or informative way.*
GRAPH #2: INTRODUCTION OF NIPPLE-SPARING TECHNIQUE

ONLY 17% OF RESPONDENTS WERE INTRODUCED TO THE NIPPLE-SPARING TECHNIQUE BY A PHYSICIAN OTHER THAN DRS. MAXWELL AND WHITWORTH. DESPITE ITS EFFICACY, AND PROVEN BENEFIT TO THE OVERALL OUTCOME IN BREAST RECONSTRUCTION, WOMEN ARE NOT MADE AWARE OF THIS TECHNIQUE AS AN OPTION.

“And then I talked to another breast surgeon that... She said that she would recommend removing them, but she said just because -- the only reason that she would recommend it is because it just seems safer. But I asked her if it was a big deal to remove them later and she said no, it wasn't a big deal to remove them later. So I thought, well, it was a big enough deal to me at the time to keep my nipples. But I just thought, even if it meant another surgery later -- but didn’t... studies at the time didn't really show an increased risk. I thought it would be worth it. Of course, things change all the time. Recommendations change every day”

"I wanted to know how safe it was because I wanted to do, definitely, what was the safest option. And he said that it had been done some years back and then everybody kind of got away from it. And then, they're starting to do it again within the last five or six years. And when he told me that when people had a recurrence of cancer, it wasn't from the tissue that was behind the nipple, I kind of thought, ‘Well why not try to save the nipple then?’ Because to me, that was -- having my own nipples instead of something made to look like a nipple that was -- for some reason, that was a very significant thing for me and to kind of -- hanging on to as much of myself as possible.”

“... (my husband) talked to several of his close friends who are oncologists, and they had not heard of the nipple-sparing. They actually treat breast cancer in this Nashville area and surrounding cities, like Murfreesboro, outside of Columbia... still localized within a 45-mile range of Nashville. No, they had not heard of nipple-sparing, and definitely they had not heard of not having chemo. Of course, they're oncologists and that's what they want to do, because that's their job, and that's how they beat, breast cancer. So this was all a new concept to them, and they were very upset that I would not go ahead and have the traditional way it's done. I had to personally talked to a couple of them, because they're my friends too, and I said, ‘this is my choice, this is what I'm gonna do, so thank you for your opinion, but I'm moving in the direction that I want to go in.’ And that's how we did that. And no, they were not familiar with any... the reconstruction part they were
definitely not familiar with at all, in particular, like in Murfreesboro, they have a standard way they do the surgery, the mastectomy, if you go in for a bilateral mastectomy, this is what you get, this is what you’re gonna look like when you’re done, that’s it. It’s nothing like what I received...”

“... That was the first time I had ever heard of that, and it was very comforting. And knowing him and what he has done in the past for people that we have known, I chose to go with him. And actually ask him for a recommendation on breast reconstruction, who do I go to from here? And he said, ‘well, I would really recommend Dr. Maxwell’, and I had heard of Dr. Maxwell prior just being in this area, so I got an appointment with him and got his opinion on what he could do, and very encouraging, and that’s how I ended up with him...”

“... I was at first very scared, because I didn't know what to expect until I did see photographs of people that had had it done. At first I thought that's not too bad; it’s not like I was expecting it to look, because they can create a nipple for you, and that was a big concern of mine, but once I found out I was allowed to keep mine, and Dr. Whitworth felt like, we don’t need to take that away if we don’t have to. We’re not gonna do it just because that’s the way people do; we’re gonna do it because that’s what’s best for you. And once... yes, I would love to keep my nipple, and when I look at my breast, it looks more like it did before anything happened. So I was excited about that...”

“No, it wasn't discussed...”

“The breast surgeon said with my situation, that I could probably keep my nipples...”

“No, no surgeon had ever discussed that with me...”

“Knew nothing about it; did not know it even existed...”

“Probably discouraged... Just because they were in fear that if the breast cancer did return, it could possibly return in the nipple area, under the nipple area, and Dr. Whitworth said in all his years of training and his experience that he had, it never returned in that area. That's why he felt very confident in nipple-sparing...”

“... The breast surgeon was playing a role, an important role... It was never discussed; that being an option. I didn’t find out about that being an option until I talked to Dr. Maxwell. It was never presented as an option by him or this plastic surgeon that I first went to.”

“... I don’t remember that ever being discussed. No, I didn’t...”

“The oncologist told me that there was a doctor in Nashville that was doing skin and nipple-sparing mastectomies, but he could not remember his name, and he would find that for me, but before he ever got back to me, I had found it and had an appointment...”

“Yes, with Dr. Maxwell.”

“I had decided it was not leaving. Actually, my surgeon actually got pretty angry with me. He wanted to go ahead. He said he was a surgeon and that in order to beat this that I would have to have my entire breast removed... I quit seeing him. I did not want to go back to him after he got angry with me when I was just trying to get it done the way I wanted it done. I was terrified...”
“... the doctor, I try not to think of his name... never discussed with me the type of implant, nothing. He just put that in... I remember asking him why a round one and this was like after the fact. Why not a shape... oval... or something and he said ‘because they move around’ and I said ‘what about the nipple’ and he said ‘well we’ll just tattoo that on, you can come back later. We’ll just tattoo that on’...”

“... Even though I read about skin-sparing and nipple-sparing, I really didn’t know what they were other than just a visual that I could get in my head... I still felt like I was going to have these big scars just right across the middle of my breast because when you go online that’s mostly what you’re going to see. That’s the visual picture you see out there... I don’t know that I actually saw other than a drawing, a picture of a woman’s breast that had had skin-sparing or nipple-sparing. The only actual pictures were women who had... that had that huge scar across it... So, it took me about a year to get into my head that, even though I may come out with a big scar on me, I still have to do something. So when I was actually able to see a picture it was like I’m going to look normal... I was thrilled at that point. I was still ready to go and do what I needed to do... I wasn’t going to be happy with it, but I can live with it because it was going to take that fear away from me of the cancer coming back... But then when I found out that was possible... well I would have done this twice if I’d known about this (laughter).”

“... he said ‘I think with this... yes, we can save your nipples.’ So, in... that was a really new concept then. That’s just amazing...”

“He’d rebuilt my nipple... he just said that it’s just best to get rid of all tissue in the area.”

“I think if I’d kept the nipples I would always wonder if I was going to get cancer... I never want to go through chemotherapy again... if there was one cell left in the nipple, I’d... I would have never forgiven myself, if I’d left them... To me, the physical appearance was not worth the peace of mind knowing that I had done everything that I can possibly do to prevent the cancer from coming back that is top priority for me, far more so than the aesthetic... but if you gotta do the aesthetic, let’s do it the best that we can.”

“... I had a graft, nipple graft, which was a whole odd, very odd thing, and it’s just kind of funny that it didn’t occur to me that the nipple graft came from the groin area, and so then I started noticing a few weeks later that I had hair on my nipple, and I realized, oh God, I have pubic hair on my nipple. Can someone explain to me where this body part came from? Oh me... So that kind of lightened the mood.”

“... The nipple had to be redone. I had nipple reconstruction on one side and augmentation on the other side. I guess it’s okay; it is, there is a difference between the real, the side that didn’t go through nipple reconstruction, which was non-implant side, and the side that was implanted. But there is a nipple there and areola... The coloring, the pigmentation is pretty good, but it is not an exact match but I’m, I guess because relatively speaking, it looks so much better than what it did before when it was left after the first plastic surgery.”
3. **Was nipple-sparing encouraged or discouraged by other physicians?**

Despite the proven safety and efficacy of the technique, women were often discouraged from deciding upon this procedure when discussing this option with other physicians. Many women concluded that the doctors seeking to influence their decisions had either limited knowledge of the safety of the procedure or did not feel they could perform the procedure themselves. Respondents believed that these were not sufficient reasons to discourage a patient from a procedure that would likely improve her visual outcome and resulting quality of life.

**GRAPH #3: REFERRING PHYSICIAN SUPPORT OF NIPPLE-SPARING TECHNIQUE**

80% of referring physicians discouraged the nipple-sparing technique when either introducing it to the patient or responding to questions presented by the patient.

4. **Was the topic of the nipple-sparing technique presented neutrally?**

“... and then nipple-sparing was discouraged by one breast surgeon and encouraged by another.”

“Just neutrally.”

“... it was discouraged by the breast surgeon...”

“No information.”

“Not before him, not before Dr. Maxwell.”

“... I think there could be more information given to other doctors to give to their patients, because I met several people who didn’t even know... they had the procedure done differently, because they had to go to a doctor who didn’t know anything about nipple-sparing, didn’t know about the way to do the reconstruction, so it would be very important for them to have that information and be aware themselves, the doctors, so they could pass it along to the patients and tell them these are your options, not this is how we do it here. Give them more information...”
“... that it is all a personal decision. Some women need that femininity for their self-esteem. They need to feel whole and they need to feel that they look good in order to have a good quality of life. It is really something that needs to be discussed. It is always on a personal basis. Every person might feel different about it. My sister seems to be totally comfortable with not having her breasts. Of course, she is not married or does not intend to be. I think it is something that definitely needs to be if a woman wants it done, then they should encourage it and give her all the options and show her what can be done rather than not do anything.”

5. What type of mastectomy did you chose Nipple-Spearing or Total Mastectomy?

GRAPH #4: MASTECTOMY TECHNIQUE USED

![Graph showing mastectomy technique used with 47% TM and 53% NS]

DESPITE THE FACT THAT 80% OF PATIENTS WERE ADVISED AGAINST THE NIPPLE-SPARING TECHNIQUE, BY REFERRING PHYSICIANS, 53% UNDERWENT THE PROCEDURE WITH DRS. MAXWELL AND WHITWORTH AND WERE GREATLY SATISFIED WITH THE RESULTS.

C. Referral Relationships

1. Was there a chain of referrals that led you to a breast surgeon and/or plastic surgeon for the mastectomy and reconstruction?

To ensure women understand their options in breast reconstruction, we must first recognize the chain of referrals that lead a woman through the process of diagnosis and treatment.

Women report their gynecologist as the first referral source in breast cancer, yet also consistently report that this specialty has little knowledge regarding advanced procedures.
Overall, most other specialties involved in cancer treatment were also reported to have limited knowledge of the option available in breast reconstruction.

**GRAPH #5: REFERRAL SOURCES**

Respondents reported that General and Breast Surgeons provided referrals to a Plastic Surgeon 44% of the time.

98% reported that Gynecologists referred them to the General or Breast Surgeon; however, 25% report that Gynecologists were the direct referral source to the Plastic Surgeon.

Most respondents report that Gynecologists are the first source of information at the time of diagnosis, but that such specialists have very little knowledge of Breast Reconstruction information to offer patients.

“... No, none, they just gave me the referral to the surgeon and that surgeon’s the one that gave me... And that’s the one that said, ‘this is the way it is. It’s all cut and dry... This is how we do it’, that’s what she said...”

“... actually I went to one plastic surgeon in Jackson. It was real quick. He just kind of came in there, told me what he would do and I asked him if he had pictures or anything that I could see. He said, ‘no’, he did not do that. I left there a little scared and I told my husband, no that is not where I am going. That is when I talked to my oncologist. He referred me to Dr. Maxwell and really any information I had came from him...”

“... I was referred by my GYN to Dr. Pat Whitworth, he pretty much said the next process would be the reconstructive, and he referred me to Dr. Maxwell. Also, my oncologist kind of worked with me through when I was going to do the reconstruction, as to when I was going to start my chemotherapy, so I felt like with me being young, I felt like they felt it was important as well.”

“... from the bottom up they need to know and they need to be able to tell a woman what her options are... When I say from the bottom, I’m talking about from the gynecologist from the general
family physician... all of those people need to be able to stop and say you need to go to a specialist... I find it absurd that they wouldn’t do that... I have nothing against general surgeons; I’m not bashing them by any means, they have their purpose... but, if I was a physician and somebody came to me and they had a problem with their throat, I wouldn’t send them to see a foot doctor because that’s just not what they deal with and that’s the same thing with general surgeons... Sure they can do surgery they can do operations but they don’t have that mindset that this is what needs to be done for a woman. It needs to start from the bottom up and everybody needs to know that to best help a woman, they need to send her to somebody who can best help...”

“The first point of referral was the gynecologist. Yes. The general surgeon did the lumpectomy. Uh hmm... or a biopsy... It was called a biopsy... because he didn’t take the whole thing out... Yet he said ‘we got it all...’ Well, he thought that he got it all and that it looked fine... And that he didn’t think it was cancer... but he had said something about they had it frozen, he had... that was a frozen specimen and so they sent it for the actual pathology... And I had to come back in, and I remember I was sitting in the room waiting for him to come in and the first thing he said to me... said was, it came in, and, well, ‘I have some bad news...’ I knew right then what that was... and he said, ‘we need to set up an appointment for a mastectomy for you...’ and I thought to myself, ‘I’m not having that done here in Clarksville’.”

“... I don’t remember anyone saying or want to actually go on the limb and say this is best as far as plastic surgeons... I don’t know if that was a personal referral between those two doctors or that it was a professional referral... I don’t know how they decided on how they referred... My gynecologist really never asked me afterwards what I thought about different folks... I was very unhappy with the person I’d been sent to on the breast surgery... the nurse told me they’d been running about 50/50, with that procedure.”

“... she did my husband’s... She’s an oncologist, a surgical oncologist, and so I thought well he had had colon cancer and he had the first colon cancer surgery in Clarksville, but then it came back a year later, and so we decided to go to Nashville and he got Dr. Grou and we had thought that he was gonna have to have a bag because it was the second... she was able to do that so that he didn’t have to have a bag and so I thought, ‘wow... if she was able to do that for him somehow, maybe she can do something for me...’ So I went to her and I thought, ‘Well if she couldn’t, maybe she could refer me to someone else.’"

“... she put me through a lot of testing and so I just felt like that throughout the testing and such that she did and meetings and everything that that was the only option... she did the mastectomy... she referred me to Dr. (redacted), he’s a plastic surgeon in (redacted-major university hospital system). He did the tissue expansion and the implant surgery... from the time he put that tissue expander in... way up too high... up to my collarbone... It didn’t make sense where the pocket was... It didn’t...”

“... the breast surgeon did the biopsy... he referred me to another plastic surgeon... we met with him, I didn’t like him at all. So at that point, I started doing my research, and talking to friends and so forth, and Dr. Maxwell had done some work for a friend of mine who has twin daughters and they had deformity with their chest, and so he’d done surgery for them at a very, fairly young age... So that’s how I met Dr. Maxwell”

“Well, the radiologist actually delivered the news... they did the mammogram, they took me immediately to the ultrasound, came back to get photographs... they had me wait and talk to the
radiologist, who was reserved, but she repeatedly said, ‘It’s very concerning.’ So, in the speed of which they wanted me to go and have a biopsy, you’re pretty prepared that it’s not going the right direction... I was with radiology and they were sending me to the breast surgeon the next day.”

“My surgeon was who my gynecologist referred me to.”

“... There was a gap with the surgeon’s office... at the time they referred me, there was a change going on in that practice... I guess the group that I thought I was going to didn’t turn out to be the one that doctor was with... Had I known more about that, I would’ve done more investigating on the guy I ended up with as far as the breast surgeon... he’s really the one I was... I’m most unhappy with, and we’ll talk about why... the group was changing, the group related to Baptist was changing, and Dr. Maxwell works with the other breast surgeon a lot, his name is Pat Whitworth. Okay, that’s the group that I was meant to go to... unbeknownst to me, the group was splitting and Pat Whitworth and some others were going one direction and the one that I ended up with was a new guy they had brought in from Florida...”

“... I think I just sort of fell through the cracks...”

“... In hindsight, I’d have stopped right there when they were trying to rush me in the first place they could...”

“... So he sent me to a general surgeon to have him review my ultrasound graph and he said, ‘well it doesn’t really look good’, but he said it did have irregular margins but he didn’t explain to me what that was... If he had said, ‘irregular margins sometime means that it can be cancerous’, I would have stopped then and there and backed out of his office and went and found somebody else that dealt with breast cancer... But he never said that it looks suspicious... ‘I want to go in and do a biopsy’, is what he said... it turned out he did a lumpectomy... when I went back to him ten days later, I consider myself an educated woman, but I never thought of it being cancer...”

“... I went to my gynecologist and he checked and he felt a lump and sent me to have a biopsy and from the biopsy I went to the doctor who had done my husband’s cancer surgery... I had a mastectomy of the right breast and then I was referred to a plastic surgeon there at (redacted-major university hospital system).”

“... my gynecologist had to get the diagnosis...”

“... that Monday I went in, I had a mammogram and then they did an ultrasound and the surgeon was there... just a general surgeon... she listed off several and so I chose one and he happened to be in the hospital that day so when I got the ultrasound, he came down and put a pin in it and then we scheduled a biopsy the very next day on Tuesday... He was a general surgeon... my sister’s best friend had come to Dr. Maxwell.”

“My gynecologist arranged for the mammogram, and so I went there to imaging center and they referred me to the group associated with Baptist...”

"He is an oncologist... my oncologist referred me to Dr. Maxwell..."

“... honestly I don’t know anybody in Clarksville that does this type... of work. And... whenever seriously, when I looked at Dr. Maxell’s website and all that, it’s like you want it so bad but it’s not
within your reach, and so it was like a Godsend whenever my sister called and he said that Dr. Whitworth had recommended you, and had set up an appointment for Dr. Maxwell, I couldn’t believe it, but then like I said, I remember thinking through the whole thing whenever he took some of the pictures and he showed me what I had, and then what I could have... And then I’m thinking I could have it but I can’t because I can’t afford it. So I was prepared to go out depressed even though because I was like that close. Anyway, I’m really grateful to that guy...”

“... It was the gynecologist... says, ‘I think I feel something there but I’m not sure...’ He said ‘because your breasts are so dense, big’, and he said ‘but I’m gonna send you for a surgeon next door for a biopsy and same day surgery thing...’ So I remember going to the surgery and the doctor, the surgeon came back in and he says everything looks fine... looks good, but I think we got it all... you need to make an appointment to come back in a period of time. I don’t remember how long it was...”

“... I told Dr. Whitworth I wanna see Dr. Maxwell ‘cause I had consulted with him back in ’03, if I ever had to do it... he said, ‘no, he doesn’t take insurance, try this other plastic surgeon...’ Well, this plastic surgeon went from going in to have surgery, he had broke his arm, he’s gonna try to do surgery on me, then he went out of business, I don’t know exactly what happened so I said, ‘Dr. Whitworth, I am so sorry, I’m gonna try to get Maxwell to you’...”

“... From my oncologist...”

“... just a general surgeon...”

“... The breast surgeon referred me. They just, they called, they got me in the first place that could get me in...’

2. How did that process lead you to find Dr. Maxwell for breast reconstruction?

To understand the process women undertook to find a surgeon who would make advanced options available, respondents were asked to describe steps which identified Dr. Maxwell as the best choice for achieving their goals in breast reconstruction.

“I think I was just trying to find the best surgeon to do my mastectomy first. That was my first goal. And so that’s how I found Dr. Whitworth. And he said that Dr. Maxwell was the best. And I went and talked to a couple of other surgeons as well. And I had actually planned to go outside of Nashville originally to have reconstruction, but I just never thought about someone like Dr. Maxwell being in Nashville. I had planned to go to Los Angeles. I thought that’s where I needed to go for breast surgery. Then I started doing research and decided that this was definitely where I needed to be.”

“... Until I got to Dr. Whitworth there was no interaction. None whatsoever and it was all up to me. I was having to do everything. I had to find my own doctors; I wasn’t being recommended to someone. I don’t know why they didn’t share my medical history with each other but just think that I started over. Once I got to Dr. Whitworth he and Dr. Maxwell worked together as far as my medical and the physical. Between the two, meaning Dr. Whitworth in medical Dr. Maxwell being the physical...”
“That's hard to say because the referring surgeon just said he's the best. I mean he didn't say why he was the best. I just kind of had to find that out on my own. And so I don’t know that. He didn’t explain why he was the best. That was something that I just kind of had to research on my own and kind of figure out on my own. But after doing that, and after talking to other plastic surgeons, I felt like he probably was the best.”

“... he’s a general surgeon but their office... they specifically concentrate on women who need breast surgery. So he’s the one that did my lumpectomy and he’s the one that recommended Dr. Maxwell as well... he said ‘if you can afford him, he’s the one that I would recommend’.”

“... on the second one I developed capsular contracture again... and I came to see Dr. Maxwell.”

“The nipple had to be redone... reconstructed... I lived with it, I tried various... there’s a shop at Baptist, which is where I go for a mammogram and I tried various things in my bras from specialty shops, but it was very lopsided and I had to be very careful in sweaters and things of that nature because when I look in the mirror I go, ‘Oh, you can see’, so, it was visible to me. And I thought somebody else would notice that as well...”

“... I just decided to check back with the office and voice my concern about my asymmetry and about the study and they booked an appointment with Dr. Maxwell and he looked at me and thought he could improve it and I weighed the possibility and even though it was still major surgery and he’s spent a lot of time in surgery with me on both breasts ‘cause it was major, it was new implants and reconstruction to make them more match and he did an excellent job and with a reasonable disposition of compassion to me about how it looked, how it would look, and how he can make it look. And he did what he said...”

“... she was very proactive and did a lot of research and researched plastic surgeons in the area and she came up with Dr. Maxwell, and she had a double mastectomy with the 410 implants...”

“... I know that I wanted something done. I knew that reconstruction could be done. I was not sure about all of the ways it could be done. Like I said, just to feel whole again, I wanted it done. When I came in and talked to him, he explained to me what he could do and that is what made me decide...”

“... And so I started this journey of reconstruction ‘cause it was a journey then, Dr. Maxwell and his nurses were extremely helpful, friendly, his sister was on front desk and she knew your name and we went into the office and it was all this yellow silk and white French provincial kinda feel, it was a beautiful office ... so I figured out of that experience, I was not going to have a paper cup taped to my breast, the hospital gown where the hole like where men waiting for surgery got to see that oh she’s having breast surgery... I felt really good about the environment, I felt really good about what the pictures that Dr. Maxwell showed, ... it felt like the kind of care I was gonna receive was excellent... a patient showed me her reconstruction and said, ‘feel this...’ I know we have a lot of friend experiences, just experiences like that that meant the world to me and made me feel like I was moving into a safe and caring environment where I was going to be on a journey, but it was going to be a journey that was gonna have a kinda happy ending... I always felt that way...”

“... I’ve had in my hand a list of doctors that was highly recommended by Dr. Whitworth and Dr. Maxwell at the top of the list and they said that he does the best work. As soon as I heard that I
thought... ‘If I’m going to go through this I want the best outcome that I can have.’ So that’s why I came to Dr. Maxwell...”

“An oncologist that I saw, she said, ‘I see everyone’s work. I wouldn’t go to him.’ And then after looking at everyone’s work... The first thing I want to see is somebody’s book. And I want to go through everything. And after going through everyone's books, I immediately dismissed what she had said. And then I talked to my gynecologist about it and she said, ‘I think that we all kind of tend to gravitate towards people that we know, and we know people that are in our same age range and we kind of refer to... you refer people to people that you have lunch with.’ And she said, ‘That’s just kind of what happens.’ And, so I think that’s why this person is referring you to that person. So I kind of had to just take things in the context of thinking, ‘Who do I believe is going to be the best for me?’

“I think the combination of things that made me uncomfortable. From everything from the office setting, and how the staff handled you to how they do the photographs. I mean everything was a bit unsettling. It was just, the atmosphere didn’t lend itself to trusting someone to do this, I guess. That they really cared about you personally, at least it was totally different, it was a 180’s different from the experience at Dr. Maxwell’s office versus experience at the other plastic surgeon, this could not have been more different in every aspect. I mean, I just can’t emphasize that enough. Every aspect, from the person that checks you in, to the nurse that takes you back there, to the way they handled taking pre-op photographs and everything was just different... it was quality, personalized, private. I felt like they did so much; they’re very much more in tuned to respecting your privacy at Dr. Maxwell’s office versus kinda the other place, it’s just sort of stand up against the wall, take your picture. I think, it’s everything, it’s not one thing in particular. The bedside manner of the doctor, physician themselves, I mean everything... Dr. Maxwell said, ‘I don’t see any reason why this can’t have a good result’, and that’s what she is wanting to know is what is the likelihood that we can have a good result at the end, and the other was just like, this is what we do, and no I don’t know that it’s going to be better than it used to be...”

“I came back to Dr. Maxwell; I wouldn’t go anywhere else, and not even consider going anywhere else... I did a little more research actually, I kinda researched now we have the internet and we all Google anything we want to, now and I googled implants and surgeons and really his research is the research that popped up all over the place... my son-in-law is training to be a plastic surgeon, and he said ‘if you had Dr. Maxwell, so I think you should go to him again, don’t bother with anyone else’...”

D. Female Perspective on Visual Outcomes and Quality of Life

This section highlights the critical importance women place on the visual outcome of breast reconstruction as a significant factor in quality of life after cancer. With courage, women explore their relationship with beauty and self-confidence, and bring valuable insight concerning the role both play in the healing process. Overall, respondents express strong beliefs that self-perceived beauty is a core element of femininity and almost uniformly they express an equally strong belief that the visual outcome of breast reconstruction is undervalued by the medical community at large.
GRAPH #6: ROLE OF VISUAL SATISFACTION IN THE HEALING PROCESS

100% OF RESPONDENTS ASSIGNED A SIGNIFICANT VALUE TO THE ROLE THE SATISFACTION WITH BREAST RECONSTRUCTION PLAYED IN THE ACTUAL HEALING PROCESS AFTER CANCER.

1. What value did you place on the aesthetic outcome of BR at the point of diagnosis on a scale of 1 to 10?

GRAPH #7: IMPORTANCE OF THE VISUAL OUTCOME TO THE PATIENT AT THE POINT OF DIAGNOSIS

78% OF RESPONDENTS STATED THAT CONCERNS ABOUT THE VISUAL OUTCOME OF BREAST RECONSTRUCTION WAS THE SECOND THOUGHT THEY HAD AT THE POINT OF BREAST CANCER DIAGNOSIS -- THE FIRST WAS “WILL I LIVE?”
“... At the time of diagnosis, I had thought, ‘Okay, they’re gonna have to do something, and if they do something, what am I gonna look like?’”

“... To me, to have gone through the reconstruction to look like that would be a constant reminder that you had cancer anyway... every time you look at yourself to see the... you wanna do it for aesthetic purposes not necessarily just to have tissue there for clothes though that is an important part... But most of the time you have a bra on, you don’t see ‘em anyway but still every time I would get out of the shower, to see the scars, I didn’t want that. I did not want that...”

“So, it’s interesting because you start in a place where the first thing on your mind is let’s just cure me, but somewhere you evolve into let me be beautiful... If we’re gonna do this, let’s do it right...”

“Ten.”

“... At diagnosis? A high value, I’d say a ten...”

“One or zero, it’s just was not in my mind.”

“... I did the surgery in the summer, and in the fall, went back to school, back to teaching... after a year of dealing with that, and I swam, so once I healed up, I was determined to go back to try to regain my health and better strength... All of that were major adventures under the circumstances. It worked for a while but I still wanted it to be more normal looking for my own self, and mate...”

“It's pretty important. Eight, I guess...”

“... I made a comment, ‘I want my whole life back, I don’t want just a part of my life back...’ It’s pretty high. I think oddly enough, I think it was probably more important to me than it was for my husband...”

“Nine, it was very high. I saw what I went through with the diagnosis and the lump the biopsies, two lumpectomies, the mastectomies and then the reconstruction. I saw that as first and foremost survive the situation to live, and so the aesthetics just, I was concerned about how I looked and I did the things like the bras to help that, but my first thought was, in going through the initial phase, the first stages of this was surviving, however it came out looking... And then my thoughts turned after I survived it to okay, can it look better? Well, it’s not that I didn’t think it was possible, it just wasn’t something I was worrying about at the time, I was more am I going to survive this? Will I be alive a year from now? And as time when on, I took supplements and tried to improve my health.”

“Eight.”

“Visually, ten. It was ten. Yeah.”

“... Something that I’ve wondered, I don’t know why, the Komen Foundation just doesn’t get involved in education on breast reconstruction... They’re always hammering away on mammograms and things of that sort and preventing it or at least staying on top of it, but it really doesn’t give any type of hope, well, if you do have it, then what?”

“... after I learned that I was not going to have the scars I put a ten on it... even though I was prepared for that, when I found out that I was not going to have that, it just made me want to do it
more. I was going to be able to have everything that I wanted at that point in time. And lose the fear...”

“... I think when you are first told you have breast cancer and are gonna have a bilateral mastectomy, I think at first I was feeling, I will be left with whatever I am left with, because I didn’t know what my options were. Once I found out what my options were, I was like, I will definitely choose this procedure, because it’s going to give me the best outcome, and I’m gonna feel better about myself. It was very important...”

“... I really had not talked to people or seen anybody that had gone through cancer ‘cause most of the women were 60-65... at 50 I felt that it was very important...”

“... At the point of diagnosis, actually I wanted a reconstruction and, of course, I wanted it to look nice. So I will tell you I had no clue how it would look, other than I had seen these pictures...”

“... the aesthetic outcome, it’s very important to have a good aesthetic outcome. That way, you can feel good about yourself...” But what I would say... if it was a newly diagnosed person, I would say it’s a long road. Give this year up because it’s a long road...”

“... I guarantee you that I thought, even if it’s not forefront, that thought of ‘what am I going to look like?’ is going to be there and that’s as much as ‘am I going to live and make it through?’”

“... The question becomes how often does that fear drive the choices about treatment? The girl that I was talking about had already had cancer and had children, had BRCA and she was not going to have the bilateral mastectomy even though it was recommended but she did so because of the outcome of the appearance... That was actually controlling her making that medical decision... the physical condition of what she’s going to look like.”

“This is the piece that is so important about making sure that the general public understands what’s possible, and that doctors are striving to raise that bar of visual outcome because it is influencing treatment outcomes. And we’re losing women, we’re losing people to that decision making tree... I know there are a lot of women out there who will not have a mammogram because they are afraid that they’re going to have cancer ‘cause they’re afraid they’re going to lose the breast... They give up before they even started...”

“...Well you can’t get better unless you feel good. And if you don’t really look good, in your mind, if you don’t look good you don’t feel good. You can’t fight off cancer. You can’t prevent reoccurrences. You can’t do things if you’re not positive about yourself. You have to be positive about yourself in order to stay healthy.”

“Beauty is defined by different people... To her sense of beauty, it’s very important; especially because that’s the way everything is defined these days, like TV, magazines, that sort of thing...”

“When you are diagnosed, and you are just shocked, all you can think about is, ‘I'm possibly going to have my breasts removed, and I'm never going to look the same again.’ But when you look at his before and after, you can see what he can do with nothing. And it’s unbelievable.”
2. How important do you believe your satisfaction with your physical self is to your healing on a scale of 1 to 10, 10 being optimal?

**GRAPH #8: ROLE OF VISUAL SATISFACTION IN THE HEALING PROCESS**

![Graph showing role of visual satisfaction in the healing process]

All respondents rank the importance of the visual outcome in breast reconstruction in the upper percentiles when asked what effect they believed it had on healing.

3. When you feel confident with your physical self, does it give you a sense of victory over disease?

One hundred percent of the respondents said that they had a sense of victory over cancer as a result of confidence in their physical self.

4. How valuable is that confidence in your physical self to your ability to move forward after cancer?

Importance of confidence in physical self to move forward.
GRAPH #9: ENHANCED ABILITY TO MOVE FORWARD AFTER CANCER

83% of respondents believed that feeling confident in the visual outcome of breast reconstruction enabled them to move forward after cancer.

5. When you feel confident about your physical self, does it enhance your relationship with your partner?

As respondents are asked to explore the concept of beauty in depth, they link self-perceived beauty to self-confidence and as the result attempt to measure the indirect impact of beauty on their intimate relationships.

GRAPH #10: ENHANCED RELATIONSHIP WITH PARTNER

Over and again, respondents noted that their satisfaction with the visual outcome of their breast reconstruction enhanced their relationship with their partner.
Respondents were asked how they would scale the following areas as impacting their relationship with their partner, on a scale of 1 to 10.

6. That feeling confident enhances communication?

**GRAPH #11: ENHANCED COMMUNICATION**

63% of respondents felt their satisfaction with the visual outcome of breast reconstruction directly impacted their self-confidence and, as a result, significantly enhanced communication with their partner.
7. Ability to enjoy life together?

**GRAPH #12: ENHANCED QUALITY OF LIFE**

70% of respondents felt their satisfaction with the visual outcome of breast reconstruction directly impacted their self-confidence and, therefore, significantly enhanced their ability to enjoy life with their partner.

8. Sexuality?

**GRAPH #13: ENHANCED SEXUALITY**

84% of respondents felt their satisfaction with the visual outcome of breast reconstruction directly enhanced their sexual relationship with their partner.
9. What value did you feel referring or diagnosing physicians placed on the aesthetic outcome?

**GRAPH #14: WHAT VALUE DO YOU FEEL THE REFERRING PHYSICIAN PLACED ON THE VISUAL OUTCOME?**

Respondents reported that approximately 40% of the physicians they interacted with placed a low value on the visual outcome of breast reconstruction, despite its overwhelming impact on the quality of life for a woman.

“I think there are some physicians that aren't going to understand that ever. And there are some physicians that I think just don't, that it's never occurred to them that some people have a higher standard for themselves than others, aside from just being alive.”

“I think Dr. Maxwell thought it was a ten. (What about your oncologist?) I did not really get a reading with him one way or the other. (What about the breast surgeon?) A zero, he was just to the point where he wanted if off whether it made me happy or not. I do not think it would have mattered to him one way or the other. I think he thought, and it probably should have been, that my health was number one and that if that is what it took to get the cancer, then I should have it removed.”

“...And so when I brought up and asked him what his opinion was of a bilateral mastectomy he said ‘yes’ and he actually said, ‘and you’re going to do reconstruction right?’ And I said ‘Yes.’ And he said that would be fantastic. He said ‘I think you need to go for it.’ He understood that without actually having me say it. Because when I had the surgery and I've been back to him since then he’s like, man, you look great. And I'm me again and he can see that I'm me again. And I feel the same way. He understands that. And I've even talked to him myself and said ‘don't send anybody else to a general surgeon, send them to a specialist if they have any questions', and he said, ‘I do’.

“My husband actually took him outside of the room and talked to him. He came back in and told me that he wanted to be productive and that he wanted to remove lymph nodes to make sure it had not spread and all that. I never got the feeling that he was concerned one way or the other about how I looked after it. I never really thought about it with him.”
“Dr. Howard, very much so because he’d seen women come in and they were just butchered, and he told me that my lumpectomy wasn’t sufficient and that I was gonna need a mastectomy and I made the decision to go ahead and do both. He said ‘if it were my wife, that’s what I would do.’ My physician, Dr. Howard a nine... a nine. He placed a nine. He said... he said ‘if you can afford Dr. Maxwell, then that’s where I would go.’ The patients that had... he had seen and treated that had Dr. Maxwell compared to other plastic surgeon... Even in Nashville.”

“... He was angry like I said. He sent me home and told me everything was okay. He then called me two or three days later. I was home by myself. He called me and told me that the portion that they had dissected in surgery was not cancerous, but the portion they sent off was cancerous and that I needed to get back in there and have a mastectomy. Of course at that point, I was just falling apart. I told him okay and went ahead and scheduled it. It was only a week later that I went back in for the second surgery. The night before I just had a breakdown and told my husband I could not do it. That is when I called him. He actually got angry with me on the phone and then again at the hospital. I would not even get undressed and put my gown on until he came in there and spoke to me because I had already signed papers prior to that to have the mastectomy. I was afraid that they would put me under and take it off anyways. Once he came in and spoke to me and got angry, saying he was the surgeon and that in order to be rid of the cancer, I need to remove the breast. I told him I would not do it... he was a zero.”

“... this is going to be crass but I’m going to say that I bet you if one of his testes had to be taken off he’d have wanted a better physician than he was to me. And he’d have wanted someone that listened to him and he never listened to me and I just don’t think he placed any importance on it at all”

“... he never spent much time with me at all. Never spent much time throughout the entire process and I remember the day I went in for the actual implant and I was sitting on the table and he was drawing the lines and measuring and all this stuff and my husband is sitting over there and they just sit there and they talked and they the doctor laughed with my husband and never really said anything to me... never said that this is what we’re going to do and what the outcome might be. They just sat there and talked and just never really said anything to me and I remember before he’s like we’ll fix it up... we’ll a... we’ll make you look good and that was just about the extent of his conversation... How could he know, he never asked me what my expectations were?”

“... I had seen him two or three times afterwards and he could see the person that I was. And of course during all the exams and stuff he could tell from before too how I was after that I was not the same person. Even with just what little bit of damage the lumpectomy did to me he knew that I needed more than just that the cancer was gone... he was a nine”

“... I don’t think they thought it was important enough. No one thinks it’s as important as you do, the one going through it, but no, I would think most of the oncologists that we talked to, they didn’t have that as a priority. But then that was low, it was to get free of the breast cancer. They were maybe a 2.”

“Well, just their comments via the oncologists that we spoke with made it seem it was not a priority. They would frequently say, ‘this is the way we treat this, this is how the outcome is gonna be, and it’s worked for us in our area. No one complained about it, they just go and have the procedure done, and they seem okay with it, so I’m sure your wife will be fine.’ They were talking to my
husband. Then on the other end of the scale, when I spoke with Dr. Whitworth and Maxwell, they were all about how do you want to feel when you are finished with this, and we want you to feel the best you can with this outcome, that’s what our goal is gonna be. We want to first of all get rid of the breast cancer, obviously; secondly, we want you to feel good about the way you look when you are finished, and I didn’t hear that from anyone else, that was the first time. So that’s why I said, ‘okay this is where I’m supposed to be’...

“My uncle was a plastic surgeon... He loved beautiful women... his appreciation for that, to be quite honest, I think that that was part of it... He appreciated a woman’s beauty. He had two sisters, one was beautiful, and his mother was, my grandmother was beautiful and I think that... that he appreciated it. And I think he thought I was young, and I think he thought that my mother would’ve been a lot happier with herself if she had chosen reconstruction...

“... When I left his office, I didn’t have any qualms about it. I wasn’t frightened about it. Before I went into his office from the previous doctor, and maybe that was my fault, maybe I didn’t give the doctor enough time to collaborate, but I think I did. I was there for about an hour and a half, two hours that day, and the meeting with Dr. Whitworth and his assistant Dee, they were just fantastic...

“Maybe a five, maybe; I was trying to think of all that was going through my mind that day...

“... I guess you could say they had pushed me for so many years to have it done, and no one had ever talked anything about the aesthetic outcome. It was very much, you need to have it done, because you have the BRCA2, and the strong family history, this is what they’ll do. Basically, we are going to remove your breast tissue; we’re going to go back, and we’re going to implant it. Then we’ll build a nipple. Never did anybody say, at the end, ‘you’re going to have this product.’ Nothing like Dr. Maxwell, who said, ‘this is what the outcome should be’...

“... I think they’re in the business of saving people’s lives, and not so, not primarily concerned with how you’re gonna live with it later. I think that needs to be done, and then there are these things that we can do after the fact...

“... Well, there was one... there was a lady at church that had had a single mastectomy and had come to a plastic surgeon down here in Nashville... I asked her, when I was going through chemo, if I could see her breast... It looked like railroad tracks … Oh yes it did, and I did not want that and I knew that Dr. Maxwell described himself as an artist...

“... I really do not know... at that point, he just did not seem to care, so I would think that his knowledge of it, or maybe it was just his knowledge of women... I think that should be a concern with any surgeon that is doing a mastectomy. I think they should take the woman’s feelings into consideration and what it is going to do to her personally.

“... When I started seeing people that did not look good was when I saw the scars... I just assumed because they were a plastic surgeon that their intent was to minimize scarring and I’ve learned that there were some surgeons to whom that was not a priority and I didn’t want that. And so, and then what I got at (redacted-major university hospital system) was like the cookie cutter and like let’s just do what we do... and you look like what you look like and it was... there was... there was very little emphasis placed on the aesthetic look. It was just literally let’s fix it and let’s put something in there and let’s go with it...”
10. What level of knowledge regarding advanced mastectomy/reconstruction, and the results that can be achieved, did you perceive to exist among your advising physicians?

“... I would say average...

“... None at all. No, and I think that, to be honest with you, I don’t know that general surgeon was the one that was going to be the one doing the reconstruction because I got outta there as quick as I could. I had no idea... I just wanted to try to find someone that would listen…”

“... No, they did not. The ones that I did not go to, as far as the ones that I did not use for the procedure, no, they had limited.”

“... the credentials looked great on paper, he graduated, appeared at the top of his class, Wake Forest, it wasn’t, there wasn’t anything that would red flag you. The red flag frankly wasn’t thrown up until D-day of the surgery. Just when we had found out that he didn’t know how to do the surgery. Dr. Maxwell was grilling him, came in, I mean the nurses literally standing there ready to give me the shot that knocks you out, and apparently he never read the note that Dr. Maxwell sent over on the procedures that we were gonna do…”

“... The options were, I needed the mastectomy on the right side. We discussed some of the pros and cons of going ahead and doing the one on the left as well. He told me that was really my choice. He told me a lot of women do decide at this point to go ahead and have both of them done. I think he gave me the correct advice as far as we don’t really have the science to prove that it really prevents anything else from happening. We just felt like for us and for our family that this was the best. The best decision that we could make at the time was that we just did not want to go through this if I had to do chemotherapy anyway. We just did not want to have to do another mastectomy again down the road... He didn’t really talk a lot about reconstruction surgery, the plastic surgeon he sent me to talked reconstruction surgery. The breast surgeon really didn’t talk to me about options about mastectomy or that they can kinda do it in tandem and start the reconstruction at the time they do the mastectomy with the implants…”

“... I don’t know, it’s hard to say. Probably didn’t know much…”

“... Um, good…”

“... yeah, he’s very knowledgeable about it but no I don’t think he knew about the nipple-sparing…”

“... Very poor. Okay. I mean he didn’t know about nipple-sparing... And then when you got to breast surgeon… of course… he’s excellent. He knew and Dr. Maxwell knew everything about it…”

“... we were going to do the nipple-sparing on the left side, we were not going to do that on the right side... so he spent a considerable amount of time trying to talk us out of that type of surgery and finally I just asked him, ‘Do you not want to do this because you don’t agree with it, or you don’t know how to do it?’ And I guess that was my first real introduction in they just don’t know everything. He, I guess to his credit, he admitted he said ‘Both…’ And at that point, Dr. Maxwell
came in and kind of re-scrambled everything and Dr. Maxwell handled it beautifully... but I would’ve preferred to have known that you don’t know... not the day of the surgery...”

**E. Expectations of Visual Outcomes Prior to Surgery**

1. **What was the perception of mastectomies/plastic surgery among you, friends and family prior to your breast reconstruction?**

Women rarely reported previous knowledge of optimal visual outcomes in breast reconstruction prior to their own experience. Most had not seen the actual results of advanced techniques in breast reconstruction, nor had their family and friends upon whom they relied for support, and, often, information.

“I’m kind of all over the board on that one. I think some people take it too far, constantly going after something that you’ll never achieve.”

“Friends, I’m not so sure. Family, just because -- my sister's history, I think that it was -- everybody kind of had a level of expectation about how they’ll... I mean we all kind of take care of ourselves. And I think everybody expected me to not look any different than I did before, really.”

“I think that was just kind of the expectation that my breast would probably be shaped a little differently because there would be a different material they were -- but I think that was really the only -- I mean I think my expectations, my husband’s expectations, my parents -- I think that we all kind of just thought that I wouldn't look that much different than I did before.”

“... It was the nipples. It was really scary. It looked like, honestly, if I had to describe it, it looked like somebody had taken them off and a child had sewn them back on. That’s the one thing I can remember sticking out in my mind...”

“Should look like natural. It should look like what I have right now. It shouldn’t look like what I had because I didn’t feel like it was part of me, it was almost like a growth …”

“Uh, I don’t know, I didn’t share it very widely. Initially I didn’t even tell my mother or my sister. I was just wrestling with what to do and getting as much information.

“I remembered that hers did look somewhat normal. That made me feel like mine could be since I already had my nipple.”

“Everybody asked me why I was doing it... And they could not understand why I was going to do it, why I would do something so drastic and it seemed drastic to them. Now my family understood. Their thought was ‘whatever it’s going to take for her to get to where she needs to be it’s what she needs to do and I’ll stand behind her and that’s her decision.’ And they have told me that. But I guess until you’re actually standing in that spot, you don’t understand it so, like my friends even though most of them were supportive, they didn’t understand. They didn’t understand what it took.”
“... Pretty much concave and everything... concaved chest but seeing the breast gone, I know I didn’t want to be unclothed in front of my husband; that was terrible and I didn’t want him to see me even with the round implant...”

“... I do not know. I had one sister-in-law that came over to see me. She thought they were going to be bigger. I told her I did not want a boob job, I just wanted to have two breasts that look the same. I really do not know. Before surgery, I always kept something in my bra, something to make them look normal to look like I had two full breasts. Once I had it done and I got back into bathing suits and stuff, they were all really happy for me that I was not afraid to get back into a bathing suit...”

“I think they were amazed that the nipple could be spared... Fascinated... some of them they’d had friends that had it 25 years ago and difference between their outcome and my outcome is actually amazing...”

“They all told me to stay off the internet. Do not look at what it looks like on there.”

“I had none, because I had not really... I knew people that had had breast cancer, but I had not seen their reconstructions, so I didn’t know...”

“... my mother had chose not, and she said if she were a younger woman that she would have. My other family members, my mother’s other two sisters and a female cousin on that side, they were very encouraging to me, but I don’t know that I really changed their mind on it or anything. I’ll wear a little tight-fitting top, and they’ll say, ‘oh, look at you’, they’ll make sweet comments and loving comments, nothing derogatory at all, that they said to my face anyway. Yeah, and I was happy to show anybody that wanted to see, but nobody really asked me. It’s better than going out to the street corner, hey, you want to see one?”

“... I thought of the way my aunt looked when she had it 25 or 30 years ago, which was a radical. It was, there was, she wasn’t left with anything. They took all the skin away. She had skin grafts from other parts of her body. That’s the vision that I had, and I think that’s probably the vision most people today have in their mind is that’s how it used to be...”

“... I had no idea. None. No. And the internet didn’t provide...”

“... Well I’d seen some people and it was really good. I mean, it was okay. But then again, I’ve seen more people who have not had reconstruction...”

“... I knew I wanted something better, I just thought there just had to be something better than what they’re offering. I just couldn’t accept that this was the best they can do. You should have high expectations, ‘cause it is possible...”

“... I was afraid there was going to be a lot of scarring. Of course, I had seen some nightmare photos on the internet of breast surgeries gone wrong. That was kind of a concern in the back of my mind, but I thought any way it goes, I have to try it. A lot of the stuff that I researched and saw, they looked really good even with the full mastectomies where they would take muscles from the back to bring around to the front. They looked good, and actually my sister-in-law and my mother-in-law had breast cancer. She had a reconstruction done with balloons...”
“... I was one whose mom had had a mastectomy and I had always said I had always thought that I was going to have reconstruction, if I needed mastectomy... might as well go ahead and have bilateral because they will never match...”

“I was scared to death.”

“I'd  never given it much thought.”

“... I had been involved with the local chapter of the Susan G. Komen Breast Cancer in my area, and I had actually seen some of these ladies breasts, and I thought, ‘oh my goodness’, I mean, they looked... I hate to say it, but they did not look good. And it just kind of horrified me, and I thought, ‘oh my goodness, I would not be showing that...’ I really just didn't know that much about it, except that maybe they would never look the same or even look normal again, because these ladies did not look normal...”

“... Just blown away. It has reset their expectations... Actually, this is true, I have two friends who are pretty much like I am we're just open and out there and they have both had just enhancements and we compared and mine looks better than theirs...”

2. **What was your personal perception of breast reconstruction after meeting with Dr. Maxwell?**

*Respondents reported a distinctly higher set of expectations regarding the visual outcome achievable in breast reconstruction after meeting with Dr. Maxwell.*

“Really, I think there were -- there were two things -- there were a couple of things that made me move away from other plastic surgeons. I wanted a fantastic result. And I had a couple of people tell me that they didn't see any reason why I couldn’t have a fine result. And it was just that word ‘fine’. I didn't want to be fine. I wanted to be great or perfect. And when I saw Dr. Maxwell he said, ‘I don't see any reason why you can’t have a perfect result’ and that word stuck with me. I think it set a standard. And, I mean, I think that there are a lot of plastic surgeons that are super confident to the point of arrogance. And I didn't think it was arrogance with him. I felt that it was a level of confidence that I think you need to have with someone that's, especially, that's going to do something like reconstruction.”

“He used the word perfect where other people have said ‘fine’. And maybe there are other people that are just as good. But I think he understood what I wanted, that I didn't want something that was mediocre. And so I felt like we were on the same level of understanding, as far as what I expected my final result to be. And he felt that he could do it. I thought my results would be as perfect as they could be”

“... I wanted it to look as natural as normal as it could be and I didn’t think the result of what had been done was that good. I thought it could be much higher but I also knew I would not go back through that, again, hoping for it to be higher... I also have an opinion I guess from being in and around this office, and around Dr. Maxwell’s environment that he was able to do, my impression was that he could do much more... much better... than what was done for me... even the other physicians and nurses, etc., his name is very well known and highly respected for his skills...”
“... I think, before, when my breast augmentation was done, they looked different; they looked fake. That’s the best way I know how to describe it. Now I feel like they look very natural, just like nothing had ever happened to them. I can’t imagine what the future has in store. If this is what it is now, because to me, this is great. I’m very, very pleased with this. In a swimsuit, you cannot tell any difference than if I was completely normal...”

“... I just wish everybody knew about him. I do...”

“... Dr. Maxwell when I came, it was like I was the only patient that he’d ever had with the level of attention... he wanted, talked about what would be best for me and my case, not just a cookie cutter type of approach and I just liked him and he came very very highly recommended...”

“... I appreciate him, because without him, all there would be would be the round implant and that’s not natural. And I was thinking to myself, especially after getting this one in and I love it, I was thinking, ‘I wish I’d had both of ‘em taken.’ (laughter)... Amazing, amazing...”

“That I would look normal...”

“... if you don’t like what you see, what you have to go through is torture... it would be just torture. When I had the mastectomy and my daughter is a pharmacist so she’s in the medical field too and one’s a nurse. They... she looked at me the next morning after surgery she said, ‘mom you look great...’ That was like whoa this is now this is worth it and it’s gotta be worth it...”

3. What is your perception of breast reconstruction based on your results?

“... I just want to lift my shirt and say, ‘These are mine’...”

“I think it can be essentially perfect. I mean that.. Dr. Maxwell told me the first time that would kind of depend on what you’re starting with. You can’t perform miracles. And I had a good starting place. And obviously Dr. Whitworth did a good job on his end of it. I think with scar tissue, which is something you can’t really predict, I had -- I mean you can’t really predict what it will do. One of my nipples is not going in the same direction as the other one. I don’t like that outcome at all. It can be fixed and I’ll have it fixed. I mean Dr. Maxwell will do that.”

“I think this was a decision that, even if reconstruction hadn’t been an option for me, I would’ve made the same decision with my quality of life. Since I was able to have reconstruction, and have good reconstruction, I know -- I mean I’m certain that my quality of life is much, much better.”

“I mean from what is available right now, I think I got the best I could get. And with my body and what's available, I think I got the best that I could get. I'm not pleased with one of my nipples going over to the side, but I think that can be fixed.”

“I think my expectations were met. Being that there was no surgeon error, there was no -- I mean, the implant that I got is, in my opinion, the best that I could get.”

“Well, obviously, my results were better for me, because there are no scars like you would have if you had your nipple removed, so that... I mean, when I look at my breasts, I don’t see anything
different. They look like they did before, which is what I wanted, and that's the outcome that I got. It was very positive…”

“It's amazing. I would say that it's very happy with it, glad that I did it. I would recommend it to anybody that's going through the same thing…”

“... you can look in the mirror and feel decent about yourself, not feel horrified. On the final reconstruction, you look in the mirror and say, 'Cool', because I look like a woman. I'm not gonna look like something disfigured or lopsided. And why that's so important to us, I don't know, or to me, I think a lot because I didn't want my husband to look at me as something not good…”

“... Oh my goodness, unbelievable... Advanced... It's crazy... because it's so beautiful... It is... it is... And normal. I mean, no one wants to look at themselves and be reminded of a part of their lives that wasn't very fun... And I never look at myself and think that... I almost have to just pinch myself and say wow, that seems like that was so long ago, like that was a different person back then. That wasn't even my life. Crazy…”

“My reconstruction is phenomenal compared to what we thought it was going to look like, given the surgeries and everything. And I get complements because my oncologist said... when we were going back and doing all this repeat surgery, ‘... that is never going to look like anything.’ That's what he said, ‘because all this has happened’... Now, he says, ‘it is good reconstruction’.”

“... I just can't explain it, I feel complete…”

4. Do you feel there is a subconscious process to the acceptance of breast reconstruction that is enhanced by comfort in touching your breasts?

Many patients identified a period of time, after breast reconstruction, in which they absent mindedly stroked their breasts, in a manner similar to a pregnant mother stroking her protruding tummy. This finding brought forth the following questions which deserve further exploration: Does a subconscious ‘body bonding’ process exist after the introduction of an internal prosthesis? If so, does the existence of this process lead to full psychological integration? In such an atmosphere, would increased emotional and sexual health, post cancer, occur?

Given recent studies showing that 75% of women are dissatisfied with their sex lives, post female cancer, the identification of various physical and psychological processes that may provide improvement in this critical area of emotional health are worthy of further analysis.
50% OF RESPONDENTS IDENTIFIED A SUBCONSCIOUS STROKING OF THE BREASTS AS OCCURRING AFTER BREAST RECONSTRUCTION. THEY WERE MADE AWARE OF THIS STROKING ACTIVITY BY FRIENDS AND FAMILY WHO WERE SURPRISED AT THE OCCURRENCE.

ONCE IT WAS BROUGHT TO THE PATIENT’S ATTENTION, THEY BECAME CONSCIOUS OF ACTION. FURTHER EXPLORATION MAY DETERMINE THIS AS PART OF AN INTEGRATION PROCESS OF A PROSTHETIC DEVICE.

QUESTIONS IN FURTHER EXPLORATION MAY IDENTIFY ENHANCED SEXUAL AND EMOTIONAL HEALTH IN THOSE WHO ENGAGE IN AN INTEGRATION PROCESS.

“... yes... feel totally it is my body...”

“... Probably did touch them, just because I was fascinated with how soft they were, but not in the aspect of acceptance...”

“...Yes, I do, and I’m not sure why I did that. And I don’t know for how long that went on, probably a month or so after the final reconstruction, and I do recall that and that you’re doing it like if you were pregnant, you rub your tummy. You’re rubbing your breasts in the same way...”

“... It must. I’m thinking it probably does...”

“...Yeah, I did that. To see what it felt like. They’re different.”

“... No, I don’t know that I did it as a nurturing act. Just overall feel. Sort of a conscious act.”

“... Probably a little disassociated that they’re a foreign object... when I move, they move.”

“... I don’t remember so much of it. I remember it occasional but I don’t remember so much of it...”
“... the saline ones you were supposed to massage... So I mean I did that, and my husband enjoyed doing that actually... except that they were just cold... that was the big change with silicone with it. He thought that was kinda fun, that was kinda fun, okay we’re going to massage them...”

“... Only when they itch and I can’t find the place to scratch... And then I think, ‘oh, there’s something not good here’...”

“... I did, I did kinda like and still like even now... it was like...for real...”

“... Probably not up until last year, no, I would not even touch them... that was just fear...”

“... No, I was just...I just feared breast cancer returning, so in my mind, I think that the less that I touched them, the further I kept it away...”

“... don’t recall that but I do remember doing a massage for the first reconstruction... the exercises to keep it from encapsulating the scar tissue... and whenever I would come back to the office, and this is the first plastic surgeon, the nurses would always remark how soft... I’m very meticulous in terms of if I got to do something a routine. I did it because of the exercises to keep it from hardening, not so much of a stroking contact. I don’t feel disassociated. I realize that it is an implant, sometimes there’s an itching I mean just a bit different from the other side but now that they look more matching, I don’t, I have never felt a disassociation...”

“... I’m very comfortable with that. And I still put gels and creams underneath for the scars underneath... and there’s still a bit of scarring here, and of course, ‘cause I don’t want to... this isn’t my stepchild... they both get the same amount of nurturing...”

“... I definitely just became more in tune with my body and really, I just had to overcome the fear and give it to God, and once I did that, and fear has been a big thing in my life that I’ve had to fight ever since the breast cancer, but I have to say that God has been so good, because He’s really helped me through it...”

“... I felt connected to my body again...”

“... I do, yeah. So kind of like ‘oops they’re there.’ Yeah I do ‘cause what amazed me most was being able to feel them and not just with my hands but my breast being able to feel my hand. Because I had in my mind that I would not be able to feel, even though the look would be there I was going to be uncomfortable ... when I was able to feel from the inside on out and outside in. It was it was like I’m me... I mean I am me again...”
5. Do you think that this process of incorporation and adaptation translates into greater sexual satisfaction and body confidence overall?

One hundred percent of the respondents to this question thought that this process contributed to overall body confidence and sexual satisfaction.

6. What was your perception of plastic surgery prior to breast reconstruction?

*Respondents were asked to compare their view of plastic surgery pre and post breast reconstruction as a method of identifying any changes an optimal visual outcome had on their overall perspective.*

“... I had had it prior to reconstructive surgery, so I was open...”

“... I've never given it much thought other than my eyes, eyebrow lift. Probably vanity... I'm definitely interested in the eyebrow lift, and I wouldn't thought that I would have ever been...”

“... I got over the perception that it was just... for vanity. I don't know. It became okay to feel good about yourself...”

“I've never given it much thought...”

“I don't know that I really had any perceptions...”

“I’d say open to having it...”
“... I think anything that a woman wants to do to make her self-esteem higher is totally up to the woman. I would definitely, if I had the money, I would probably be one of those that would have a few things done here and there...”

“... That has never bothered me. I think if it takes that for your self-esteem, then I think that it should be done...”

“... I would say superficial because all you see out there in Hollywood. Like Mary Tyler Moore who refuses to age and she looks, they almost don’t look like the same person. And so, I think because of that I would say it’s superficial...”

“... I thought it was well... in a way I thought it was superficial. I had considered enhancements and it was just me being vain. Now my whole perception has changed... It’s not about vanity; it is not... it is more about the way you feel about yourself. Regardless of what it is you’re doing. Whether you’re doing a reconstruction, whether you’re doing an enhancement it’s all about how you feel about yourself and I think if you feel good about yourself you’re going to be better not just for yourself but the people around you. It’s not about vanity. I don’t see that anymore...”

“... I think it’s an individual decision for myself, if it’s not something I have to have done, I won’t. It’s just maybe too many surgeries, too many things through the years. If it’s something that is needed to have done and will help me keep pretty much my idea of myself, I will. I’m okay with me...”

“... I would be open to it from a philosophical point of view. On the one hand, but on the other hand, I’m kind of from a granola generation too, and that being said, I did think of getting an enhancement 25 years ago, but then I just thought, well, I’m small-breasted, and that’s the way I’m supposed to be, so just let it be. As far as other procedures, I don’t know...”

“... I’ve never had plastic surgery, never considered it, and I do consider it superficial...”

**F. Sexuality**

*Respondents were asked a number of questions designed to explore the impact of breast reconstruction on their sexual health. Questions were developed to identify areas of inhibition or positive impact experienced as the result of breast reconstruction. Respondents were asked to compare their views prior to breast cancer with their views after breast reconstruction. Respondents represent women of ages 30-65, as well as varying weight and fitness levels.*

1. **How do you think this journey has affected your sexual relationships?**
79% OF RESPONDENTS REPORTED THAT BREAST RECONSTRUCTION IMPROVED THEIR SEXUAL RELATIONSHIP WITH THEIR PARTNER.

THEY REPORTED INCREASED LEVELS OF CONFIDENCE WITH THEIR VISUAL APPEARANCE, INCREASED COMFORT WITH NUDITY AND A PERCEPTION THAT THEIR PARTNERS WERE PLEASED WITH THEIR VISUAL APPEARANCE.

“... you still have the same feelings and thoughts that everyone does. You still wanted to look a certain way in front of him. You wanted him to be comfortable with your body, so I don’t know if the act itself is as important as the intimacy and that dynamic of intimacy that exists within a couple...”

“... I think it’s what’s in the couple, because there are different types of intimacy, and even though there’s not a physical, there’s that look that just sometimes the touch of a hand on a shoulder, on your back, that look to know that you have their utmost approval...”

“... I just accepted is, our relationship is what it is, without the other. But the other is still there, and I’d never thought of it still being there...”

“... I still had a little bit of weight on me, and I’ve put on more. My clothes tell me all the time. It’s like, and because of that, I’m embarrassed around my husband not being clothed...”

“... It’s very, very important. Yeah, it is a psychological thing, because the happier we can stay in our lives than let the stresses and traumas and those things that come up every day, every so often in life, the more we can be, not dwell and stay on the positive side and not dwell on the negative... it has a big effect it has on our bodies... It does, definitely does.”

“... There was a time early on where I really neglected it, I did. I was kind of afraid...”

“... He doesn’t touch them... the fact that I’m so dry and so uncomfortable and that I don’t... I avoid sex now... because it hurts. It hurts...”
2. What is your perception of your mate’s reaction to your breast reconstruction?

**GRAPH #18: PERCEIVED SPOUSAL SATISFACTION WITH BREAST RECONSTRUCTION**

75% OF RESPONDENTS PERCEIVED THEIR SPOUSE TO BE EXTREMELY SATISFIED WITH THEIR BREASTS AFTER BREAST RECONSTRUCTION.

50% FELT THEIR SPOUSES THOUGHT THEIR BREASTS WERE VISUALLY IMPROVED WHEN COMPARED TO THEIR APPEARANCE PRIOR TO BREAST CANCER.

“Right after the breast surgery, when I was having a few problems, his reaction was not good. Reaction in front of Dr. Maxwell, he said I looked like a pig. That was tough, but it did look ugly. I would have to say that one area that was not healing right, considering all that goes on with him, a very unlikely comment; because there was a time he would not have made those types of comments... It hurt. He looks every now and then, maybe will slightly brush his hand across my breast, but that's all... He says they look very nice... He has, and I think a lot of the fact that there's not a tremendous response is due to his depression, the prostate cancer, and all of this has just escalated after each thing through the years.”

“... it would be better. I was fairly young; I was just 6 months into my marriage, so that was a big thing for me. I wanted to look as normal and feel as normal as possible...”

“... That he's not afraid to touch. And he has even said to someone and I don't even recall who he was talking to, he said like with the first surgery that 'it was like Frankenstein', he said that. And he said but this one, since the surgery, and he was comparing the two... once it was over... I heard him say to someone, 'this one looks natural; it looks real', so he likes it a lot better too (laughter)...”

“... He is not a medical person. He is not a person who deals with sick. But he has been right there, right there every... and he is much more at ease with me now. So that was the big deal... He just stuck with it. I mean it was a big deal to me. It wasn't a big deal to him. It had been a big deal to me right along in talking with oncologists, because I talked to him a lot about it. But it wasn't a big deal to my husband...”
“... Well I don't really like my body because it's fat. So, we're going through that right now because we're both overweight. But it's better. I mean we feel better together...”

“... we would be in a group of people and I was still, I mean we were still relatively young and he'd say something like, 'my wife has plastic tits...' Things that really made you feel laughed at... a long talking to, and more than that, about that kinda thing, but now he thinks my body is great. He said, 'look at you for the age you are, look how good you look'."

“... I think he likes the look, but he doesn't like the touch...”

“I think he loves it.”

“Oh, probably better because I wasn’t getting any younger and they were heading south (laughter) and so I would definitely say better.”

“... There is another friend that I found out not a friend but an acquaintance at church, and I didn’t even know she had breast cancer and she had cancer and elected because she had two small children to have it done in Paducah. And he did not put any drains in and she almost died... she had to come down here... She almost died. Yeah, that’s huge, that’s huge Almost died...”

“Oh, I don’t know. We have issues there, we always have, so...”

“... it never bothered him. It never seemed to, which was good, but I guess it bothered me more than did him.”

“... He's okay with it. He likes it.”

“... He has not touched my breast. I don’t, I don’t understand why. I think he just feels there, I don’t know... It’s not something that we talk about a lot... He’s never, I guess he says, he says that he’s not a boob man, so to speak and it wasn’t that, that big of a deal anyway. I mean not to, not to, it wasn’t one of his focal issues, let’s put it that way...”

“... I think he avoids them... I just think he knows they're not real and he just doesn’t want any part of them... it still hurts a little bit I can't worry about that. But I'm alive and there could be a whole lot worse issues...”

“... I did it for me, not necessarily for him. I mean I did it for my own personal piece of mind, not for his sexual pleasure and I did it for me and I if he doesn’t enjoy them then that’s okay. That’s his personal preference and that’s okay with me...”

“My husband and I have been together for 30 years. He has been there through thick and thin, whatever. I have never worried about that with him. He is just a perfect man...”

“... My husband has always been there for me. He has always made me feel like no matter what happened to me, or he knew how I felt about the cancer. He was there to support me through it all. Anything I wanted to do or whatever, he was right there behind me telling me it is your decision, you do what you want to do. Even with that reconstruction and stuff, like I said, he told me I did not have to do it for him, that it did not matter to him one way or the other and I know that it does not matter to him..."
“… it’s taken some getting used to for him... I’ve had to do some little fussin’ about language that he had used that I felt was humiliating in front of groups. He didn’t mean to use his... like being manly, but now he’s like, ‘look at those tits’...”

“... He loves it...”

“I think I mentioned that we definitely needed to have the lights off, and he knew what he had been privy to, a lot of what I had been going through, and we’re still connected and close. We’ll never be partners again, but... and he’s been a really great support in a lot of ways, screw-up as he is. So he knew that this was not my... he said, ‘I would want to see you if you’re comfortable with it, but if not...’ it was very, it was an hour and a half actually of testing the waters (to learn) to learn and to see how I was going to respond. I really had no idea. I really didn’t know if I would... I knew I had sensation again, but I didn’t know if that connection was going to be there.”

3. Are you comfortable in all lovemaking positions, or do you guard your body?

**GRAPH #19: UNGUARDED DURING SEXUAL ACTIVITY**

RESPONDENTS WERE ASKED IF THEY SHIELDED OR GUARDED THEIR BODIES DURING SEXUAL ACTIVITY AS AN INDICATOR OF INHIBITION.

LEVEL OF GUARDEDNESS IS ASSUMED TO REFLECT A MEASURE OF SEXUAL INHIBITION AFTER BREAST RECONSTRUCTION.

89% OF RESPONDENTS REPORTED A LACK OF INHIBITIONS DURING SEXUAL ACTIVITY.
4. Are you comfortable being seen fully unclothed?

**GRAPH #20: REACTION TO NUDITY**

76% OF WOMEN REPORT COMPLETE COMFORT WITH NUDITY AFTER BREAST RECONSTRUCTION. 56% REPORTED AN INCREASE IN CONFIDENCE WITH NUDITY AFTER BREAST RECONSTRUCTION AS COMPARED TO CONFIDENCE WITH NUDITY PRIOR TO BREAST CANCER.

5. How does your self-perception of your physical beauty affect your sexuality?

*In a more in-depth discussion of how a woman’s view of herself impacts her sexual responses, women candidly explore the direct impact self-perceived beauty has on her intimate relationships.*

“I think it greatly affects it, and not necessarily me directly. I think that the way I feel about myself really impacts my husband. If I'm not feeling good about myself, I think that my personality is so different. And I think my negativity really affects him”

“Tremendously, I think. The appearance alone, I mean, I can live with the way it was, I lived with it for a year or two but I finally decided I did not like that just for me, let alone for a partner involved. And I thought something could be done and, but I would not have gone back to the first surgeon for that. And fortunately, Dr. Maxwell came and I trusted him and heard enough about him that I was willing to try and he, he proved that he could do what he said he could do... I was glad it looked much, much better. I was just pleased that it looked much, much better in terms of appearance and how it looked...”

“I think the decline has more to do with that I have no hormones at all. I think that it's just a lack of desire. Yes, that's the issue, hormones, not that it's, not that I don't feel good about myself personally or am against having sex. Yes, I think it certainly helps you to maintain your confidence. Even, even though it’s not the same... Even though your desire level may be there the desire level's not the same... I don't mean that it doesn't feel the same, but that you have no touch sensation to your breasts...”
“... It was a major impact on my healing. If I had had what my mother had with my stepfather, my mother even turned to alcohol. It just took her down. I think had I been with somebody like that, that it would probably have done the same to me... totally destroyed me emotionally, physically. She never felt whole. She never felt pretty again. Her marriage ended over it. It was really bad. I think had I been with somebody like that, I would hope that I would have been strong enough to walk away. My mother was not. I would have hoped that I would have been just from seeing what I saw with her...”

(How does your self-perception affect your sexuality? Do you feel sexier?) “Oh heck yeah.”

“Oh... my confidence level self-esteem has really risen. I was there before I was diagnosed; I was firmly there at a point in my life where I’ve always wanted to be. And then the cancer took it away. My reconstruction gave it back to me. It really did...”

G. Body Confidence

1. What feature do you enjoy most about yourself?

**GRAPH #21: PHYSICAL FEATURES MOST ENJOYED**

WHEN ASKED WHAT PHYSICAL FEATURE THEY RANKED AS THEIR GREATEST VISUAL ASSET, 50% OF RESPONDENTS CHOSE THEIR BREASTS -- **AFTER** BREAST RECONSTRUCTION.

THIS IS A DIRECT CONTRADICTION TO THE OFTEN HELD BELIEF THAT BREAST RECONSTRUCTION CANNOT PRODUCE A BEAUTIFUL AND VISUALLY FULFILLING OUTCOME.
2. How has your breast reconstruction changed your perception of yourself?

GRAPH #22: LEVEL OF OVERALL BODY SATISFACTION

RESPONDENTS WERE ASKED TO EVALUATE THEIR OVERALL SATISFACTION WITH THEIR BODIES. 36% OF RESPONDENTS REPORTED OVERALL SATISFACTION WITH THEIR PHYSICAL APPEARANCE. 27% REPORTED DISSATISFACTION WITH SEVERAL AREAS.

“... want to say, I want to say, before I treated them as an accessory, now they’re... I don’t know how to make this sound like I want it to sound... they’re mine, they’re me, they are a reminder of, I’m strong, I made it, and they’re powerful. I know that probably sounds funny, but that’s how they are for me now. They are a part of me; I am no longer afraid of them anymore...”

“If I’m truly... satisfaction-wise, I’m a ten, but there’s something back in there that says, ‘That’s not all you.’ There’s something way back in here. Every now and then, but not often...”

“I am not as shy. I’m very proud of where I’ve come from, and I don’t... I think before I was more off-limits, just kind of guarded, and I think now that I’m definitely more open and free. I know that probably sounds crazy, but I feel very free in that area now.”

“I like my new boobs...”

“It’s getting more confidence...”

“Probably more apt to show my body...”

“... I think most women think they’re going to wear a special bra, ‘cause I can say that I had no clue before I had breast cancer that this was available. And I don’t think people think about that...”

“Not guarded, but I’m not intimate a lot. I’m very active, but not guarded and much less now than before when it was so lopsided...”
“... Even when I go to swim, I tend to be a bit guarded in my changing into the swimsuit because I’m aware of the difference between them, but they, if at a glance, they look much more balanced and normal now than they did before, but I tend to kinda guard the side that had the implant on it when I change into a swimsuit at the, at the center where I swim...”

“... More comfortable before the change... even after the correction, there’s... feel some difference, but just not as much so I’m pleased with the lessening of the difference now... The effects are there inside of me as well as outside... it’s just there and I’m very much aware of it but it’s... I don’t think it’s limiting. It’s just a new awareness...”

“... I think I’m... feel like I’m a stronger person because I have been on a journey that a lot of women are just getting around to...”

“... I think if something were to happen to my husband and he were to die, I think I would have lots of men call me up for dates if I wanted it. And that sense of confidence means something to a person. I think my husband thinks that too. He admits his friends treat me in a very, really a caring and loving friend way... I feel acknowledged but they also I think they like having me around because I look pretty good...”

“... I feel I am in pretty good shape for 52 years old. I am just kind of proud of my overall body for a woman my age.”

“... Right now with the radiation scarring and stuff going on and it not looking the same as the other one, I pretty much wear a camisole. That is just for me. It would not matter to him one way or the other. It is more of, if it can get fixed, you can see it later on... Right now, I pretty much wear a camisole...”

“... There is definitely a boundary...”

“... I have no problem at all...”

“... It is the same...”

“... I probably like them better...”

“... I was never uncomfortable with my body... Once I have the revision again, I will be perfectly comfortable...”

“... I wasn’t really suffering any great crisis before.”

“... I’m pretty comfortable. It’s just very painful...”

“... I wasn’t unhappy with the breast I had, I mean they were saggy but I nursed two children and just realize that that was a part of it, and I wore push up bras. I mean I wasn’t dissatisfied...”

“... Well, at this point, I think there are aspects that I would change, and I can do that on my own, as far as exercise and that type of thing, so yes, I’m not 100% satisfied with the way I look...”
“... I guess I feel more confident. Pretty confident prior because I had implants prior, and I feel almost like I did before anything happened...”

“Very important, because if you feel confident with yourself, then you’re gonna portray that to your spouse, and they’re gonna feel good about the way you look if you feel good about the way you look, and that’s how… it’s very important...”

“... I don’t think that changed, ‘cause I had a good outcome...”

“... I’m sure it’s better, because you do feel better about yourself... than with everything else, you’re more confidence.”

“I enjoy my breasts. I know that sounds terrible... no it doesn’t... so vain or something... it does not, it sounds like victory.”

“To finally be giving myself permission to live, to go on. That it’s all good now. That breast has allowed me to do... because I’m not joking if I’d had to stay with that other one, I would have had surgery to have that thing removed. And that would have had its own emotional impact.”

3. Are you satisfied with the shape and the feel of the implants? Scale of 1 to 10

GRAPH #23: SATISFACTION WITH SHAPE AND FEEL OF IMPLANTS

ALL WOMEN INTERVIEWED RECEIVED THE GUMMY BEAR 410, ALLERGAN IMPLANT.

ALL RESPONSES TO QUESTIONS OF LEVELS OF SATISFACTION WITH THE LOOK AND FEEL OF THE 410 WERE IN THE UPPER PERCENTILE.

MANY WOMEN IDENTIFIED A DESIRE FOR ENHANCED PROJECTION TO BE INCORPORATED IN NEWER DESIGNS.
“I do have the gummy bear... They’re great. Yeah, yeah, I mean they feel really natural. They actually kinda warm up. I hated the saline; I just want to go back to that for just a minute. I was very active and I still am and I would bend over and I’d feel them. Bowling they were very cold to the touch they feel so unnatural. I was really anxious to get rid of those as quickly as I could and I did as soon as the FDA said I could and wasn’t really necessarily unhappy with the ones, the implants that I had before. I think they were the best in the market had to offer at the time but these are much better...”

“... So much more natural. Unbelievable compared to the saline... The best of the best and I’m very pleased, I’m delighted...”

“... I wished I had both of them done... I don’t know that insurance would cover it but if I knew someone that was going to go through a mastectomy and it only involved one I would tell them to get both removed... at first I remember thinking, whenever I was going to do it, I said to my husband, ‘I wonder if I should just go ahead and get both of them removed?’ That way you don’t have to worry about it and it seemed like it would be just easier to what... to match or whatever. And it would... and he’s like, no, you might as well keep at least one; that’s a man... it’s a man... I thought, ‘maybe you’re right maybe I should at least hold on to one real one.’ I was afraid to... how it was going to affect me mentally to lose both of them. But it I don’t know. I know that I rather just had them both removed. Because then that way I don’t, if they’re going to droop, with age or whatever, I think because they are of the same types they would both go. That they would respond the same way... that it’s consistent...”

“... Probably a nine, I still wish that, like I said, especially with this one that slides... it’s a special case with me because of my ribcage... this one doesn’t bother me near as much as this one does, and what is so ironic is this was the side that I opted to do the one I have trouble with... nobody knew my ribcage fell off... sloped... he just said ‘it falls off’, those were Dr. Maxwell’s words... It just does, there’s not the ribcage there to provide and just kind of slides out and off. That’s the most disappointing thing in me, but it’s the shape of my body, it had nothing to do with the fact of the implant...”

“... I see everything’s on the back drop of how it was and how it is now, it’s just such a drastic improvement. That, though not perfectly matched, it’s just so much closer that the nipple is a little lower, the reconstructed, but it is there and the color is... It seems to be a pretty good job, if not...”

“... I want to say yes. Of course the radiation and the pulling and all that kind of stuff, when I first had it done, the revision that I am about to have will be my third one, when I first had it done, yes they looked perfect, normal, felt good. There is not any problem with the implants at all. In fact, I have one in right where they created symmetry. It is perfect and you cannot even tell that it is there. It feels normal. It is just the radiated side that gives me problems. Like I said when I first had it done, it seemed to stay good for a year or so and that is when the scar tissue starts building back up... I think this time it is worse than it has been with the other ones. It seemed to come back quicker than it did the first few times...”

“... No, I love it. Like I said when I first came home, first had it done, it was perfect. They are perfect...”
H. Interest in a Comprehensive Women's Breast Center

1. Looking back on your experience would a facility dedicated solely to the care of women undergoing BR or other plastic surgery have been of benefit to you?

*Overall, women did not feel that a comprehensive women’s center existed in the local area, despite the marketing efforts of hospitals to identify their facilities as such. Women expressed interest in a fully comprehensive women’s center, but, based on current experience, were concerned that it would become another self-contained referral system, thereby, limiting information provided to women should certain services be unavailable within the facility.*

“I think so. I mean even if it was in the hospital.”

“... No, because every doctor, every hospital I went to every different hospital, I picked where I wanted to be... I wanted my OB/GYN, she’s been at Centennial, Whitworth at Baptist, Dr. Johnson was at Vanderbilt, and if I did choose if I did decide to do radiation, I was gonna go to St. Thomas. So I don’t believe having all the doctors in one group is good…”

“... I don’t think being in a total of women’s facility everybody together is actually a good thing because you can hear an opinion, this one doctor will say this, and you'll have another one that says this and you, and that gives you an idea of what’s better for you, not what's best for them or their hospital on their... the money that’s coming in, you base, based on your experience and who’s telling you what, and what's best for you, what’s best for me, is not best for you. So no, I would not say it’s actually a good thing to have all the doctors under one roof…”

“Oh yes. Just exactly and because that kinda goes back to what Dr. (redacted), with the tumor board and such because she said that they need like a group as a team to decide the best course of treatment, and how best to approach that so I appreciated that ‘cause I thought well at least she’s not just like playing God she’s making the final decision for me. So I think that a multidisciplinary approach would be great. I like that…”

“... you mean like a clinic that has everybody housed in there? A gynecologist and a surgeon and plastic surgeon, and you get to meet them all, and they’re all together? I think that sounds great. But does that happen in real life? Because, depending on how old you are, I guess, and depending on how long you’ve lived in a certain city, you hear things; people who have had work done by this and that, this is the best surgeon, and he’s the best guy for this, and so, you come in… You can construct your own team…”

“... I think where the system breaks down is that you have a somewhat integrated approach in that your file gets passed around, but it’s, we’re on the timeline that gets passed, so if you’ve already had the breast tissue removal, well, there’s a certain set of criteria that plastic surgeons have to live with. So it really depends on how those pieces come together. If that information’s being shared up front…”

“... getting two people with busy schedules together, with me in the same room, to talk about that. That’s kind of impractical, isn’t it?”
“Yes, it’s always good to have people that are going through the same things you are going through... you’d probably get better care, if they are more trained on what exactly you’re going through at the time...”

“Oh yes, definitely...”

“... Oh, absolutely, I totally believe in the multidisciplinary approach. We do that in school with kids, and I really believe that it’s the only way to... I’ll give that a ten. It’s the only way to make really good decisions...”

“... It would be awesome... It would be awesome... Too often everybody’s not on the same page, and if you have a group of people that you can go in and this, this and this, and everybody can look at the whole medical records, all of the medical records, and they can say, ‘Well, all right, here’s what this person needs.’ I think it would be awesome. I don’t know if it’s possible. I really doubt, but it would be really totally awesome...”

“... It would be awesome...”

“... you’d probably get better care, if they are more trained on what exactly you’re going through at the time that would be nice. It was just crazy to have to run to different places, so it would be very helpful to have all of that under the same roof...”

“... Oh my goodness, absolutely...”

“... I would think, yes...”

“... I think so. None of us, not even the best surgeons have all the answers... in something like this, you’ve got the disease, you’ve got the body appearance, etc... it’s like pieces, parts of a person that are handled by different professionals, medical professionals... if they are interacting and cooperating, I would think a patient gets the benefit of it, of all those minds coming together, kind of a synergy... I think the multidisciplinary approach would be better, produce better care for a patient...”

2. Are there any areas of your experience you feel could be used as opportunity for improvement for future patients?

“The scarring.... And in the drainage tubes; that affects the kind of bathing suit that I wear, but it doesn't affect anything else, really. Actually, it affects the kind of bras I wear too, because finding things that don’t rub scars.”

“Patients going through what I’m doing, they need to look at pictures. I think that’s very important when you visit a plastic surgeon... general surgeons should tell their patients when they visit plastic surgeon, to ask for pictures. Because I went to one that showed no pictures, and then I went to Dr. Maxwell that showed me a bunch of pictures. Right, I think seeing pictures is very very very important to making a decision about the type of surgery that you’re gonna have done, you need to look at some trams flap pictures, you need to look at, you just need to see patients who’ve gone through it and talk to patients that have gone through it...”
“... No, not really, 'cause once I walked into Dr. Maxwell’s office, and he spent several hours that day, he and his staff, talking to my husband and I felt better than I had ever felt. What he did when I walked in that office changed my mind; it changed my life...”

“... I think there could be more information given to other doctors to give to their patients, because I met several people who didn’t even… they had the procedure done differently, because they had to go to a doctor who didn’t know anything about nipple-sparing, didn’t know about the way to do the reconstruction.”

“... I have always been really happy with the way things have gone here. Once they are here, they have already gone through the breast cancer and stuff. Dr. Maxwell is very thorough about what I could have done, what he could do to help me, make me look normal again. I was very pleased with that. I do not know of anything I could think of that he could do that was any better than what he did with me...”

“... he told me exactly what to expect every step of the way, what to expect the outcome to be, and showed, not only said the words, but he showed things every step of the way; this is the product that we’re going to use, this is what your surgery’s going to be, this is where we’re going to cut, this is the outcome that you should have in the end. There were visuals to help with what he described every step of the way...”

“... Probably the before and after photos on Dr. Maxwell’s website... if I would have had that, I think it would certainly give you a lot of hope. Because when you are diagnosed, and you are just shocked, all you can think about is, ‘I’m possibly going to have my breasts removed, and I’m never going to look the same again.’ But when you look at his before and after, you can see what he can do with nothing. And it’s unbelievable...”

“... there’s no gatekeeper to kinda oversee the whole process... It could be a huge improvement, cause no one wants to be... the oncologist just wants to cure the cancer... I think from the oncologist’s standpoint the plastic surgeon just wants to put you back together again, and from his standpoint he can do that after... the oncologists thinks, ‘I’m doing the lifesaving here and he can do that part later. That’s not important to your life’.”

“... I think one of the things I found a bit frustrating is there’s almost no information at all on what to expect as far as how that’s going to actually going to affect your life afterwards...”

“... Don’t be afraid to question things... If you’re uncomfortable with the answer they’re giving you, maybe there’s a better answer... you’re dealing with all these specialties, nobody’s in charge... Nobody wants to be the lead dog on that...”

“... always tell them about my experience with Dr. Maxwell. I don’t have any other experience to relate it to; I didn’t see any other doctors but him, but I do know what he was able to give me, and not just breast-wise, but his office, himself, were always there to answer my questions, and in a very unstable time in my life, they made me feel very secure...”

“... Learn as much as you can, talk to as many people as you can that are knowledgeable and not just in it for the thrill ride of the... Talk to as many people as they can and be open about it. I was on the phone with cancer societies and women’s clinic groups and health groups, going, ‘what do I
do?’ ‘What do I do? What do I do?’ And I’ve talked to total strangers that would give me information over the phone... but, at the end of the day, it’s got to be your decision, but you need to be as informed with as much information as you can…”

“... We definitely need to get media behind it... the internet was great. More information that the doctors never offered... this information, no pamphlet, no here are your options, nothing. No before or after. Nothing... the ones that I had seen on the internet were just people who wanted to have implants in general... for aesthetics... and that’s a very different... that’s totally different, not the same thing at all...”

“... Even the doctors who are frontline need to have more information in their office... some of these women I have talked to that when they were talking to their doctors they didn’t mention reconstruction right away at the beginning. And I think those words need to come, ‘we can do a mastectomy with reconstruction...’ Not just the mastectomy... not leave it alone and we’ll worry about that later. I think it needs to come if it’s physically possible and medically possible so at the same time I think that information needs to be in the doctor’s office. ‘Cause I look around and I don’t really see a whole lot and the women that I talk to... it’s almost like an afterthought... women need to know right up front that you’re going to get through this. It’s going to be okay and you’re going to come out on the other end...”

“I hate to say this but in the general surgeon’s office that I went to, he has a PA that is not recommending Dr. Maxwell... she didn’t like dealing with his office staff... so he’s recommending Maxwell, and when he leaves the room, she says I wouldn’t go to Maxwell, I’d go to such and such and such... because he is so picky, he’s a perfectionist. If he says that those drainage tubes don’t come out until 10 ml, don’t you take them out when there’s 12... What she said to me is that his office staff is just very meticulous; that’s a good thing... I mean that’s a plus for the office.”

“... if you’re out of town and you come and have surgery out of town like I did, we both got a hotel the night we were released from the hospital, and so we hung around 24 hours... and then I was able to come back to Maxwell’s office for post-op... just stay in town until you have your post-op visit and you don’t have any complications. Don’t leave town until you know that...”

“... when Dr. Maxwell did mine, he wanted to make sure that I looked natural. Now if I had said, ‘hey, I want to go bigger’, he would have done that, but what I told him was that I want to look better than I did, but I don’t want to look unnatural. So I look very natural. I am very proportionate, very plain...”

“... Yeah, I would probably change the size, and at first I would probably not have said that... I would probably go just a little bit bigger, but I’m not sure that was an option for me... I think it may not have looked as good, but I guess, I think everyone was very happy with what I have.”

“... My breast has rotated a little bit, so I would want to have that fixed back into its normal spot. The fat grafting, I’ve had a little trouble with that... so I would have that repaired as well, but other than that...”

“Probably... I was large before, like a DD, and he went I think like CD. I would probably have done his recommendation. Dr. Maxwell said, ‘Why don’t we stay with a C?’ So I wanted to keep my husband from being disappointed, so I said, ‘Let’s keep it up.’ At that time, I thought it was very, very important to have my breasts as close to the same size that they were previously, so in my
mind, that would be in acceptance of my husband. Now? I think the weight on my shoulders... of course, before, my own were heavy on my shoulders, because they were even larger. So I think that more than anything, and I think actually when you get down to it, the fact that I don’t have cancer, the fact that I had reconstruction, now I don’t have to be that big. I’m okay to have them somewhat smaller. I can look now and see where it would have been more comfortable in the long run. These are very comfortable, but they’re heavy, and that’s just the way it was before, and I really thought it had to be the same. It didn’t...”

I. What would you most want to say to women facing the breast reconstruction journey?

“... if you’re coming back this way West or South, or even East and nobody tells you about Dr. Whitworth or Dr. Maxwell... now I think Dr. Maxwell’s name is out there more now, because I’ve heard other people mention him in the last few years, but that day they didn’t mention to me, and it may be that he just didn’t think of him at the time, but I’m not gonna sure put the doctor down at all. He was trying to find what he thought would be sensible at the moment...”

“Learn as much as you can, talk to as many people as you can, that are knowledgeable and not just in it for the hyper, the thrill ride of the... talk to as many people as they can and be open about it. I was on the phone with cancer societies and women’s clinic groups and health groups, going what do I do? What do I do? What do I do? And I’ve talked to total strangers that would give me information over the phone. And but, at the end of the day, it’s got to be your decision, but you need to be as informed with however, wherever, with as much different kinds of information as you can.”

“... go to a variety of care-givers for people to offer their stories, so you have information about what to do. Minnie pearl and Gilda’s Club, Gilda’s Club was one of those places where I went, and I was in a ball of tears, just a mess of tears, and this poor young girl, her name is Lauren, and she met me at the door, and she said, ‘well, let’s go talk.’ And we talked, and I started going to their guided-imagery meditation class, and that’s where I met the caregiver, the alternative caregiver, the hypnosis woman in Franklin, and I went there every single week on Tuesday for that guided imagery class, and it was so so so helpful. And she was the, that girl, at Gilda’s, gave me more real information about the chemo. This was the first day that I heard I needed to do the chemo, and I went off the wall, and I went over there and I said, ‘I’ve been told I have to do this’, and she knew the kind of drug, and she knew the trial, and off the top of her head, and just sat there with me for 15 minutes and let me bawl, and she would offer a couple more comments. People like that are really important, really important. It’s huge, isn’t it, to take the time with you, your adjustment curve...”

“... Well, there are a lot of things I guess to say. But I will say one thing that helped, a couple things that helped early on. When I first got the diagnosis, I got a, a call from a woman who had been through, but she was further along, and offered support. It seemed to me, first a phone call, then a note card, and she wrote out if you want to talk about, and I did, and we talked, and I never met her and she didn’t know me. I assumed it was some kind of sign up at the hospital where I could say whether I wanted that or not, and it just, it just was helpful to talk, interact with someone who had been through it, who had come out of it, who had gotten through, who had made it through... maybe a year or two ago I found the address again and wrote another thank you card to thank her...”

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again for that, and I never heard from her again after that. But it is, it’s, even though I say that I’m a very private, independent person, I didn’t tell very many about it, it was in support of family and close family and friends and my faith in God…”

“…I think that the better you feel about yourself, that the easier life is, the better you project yourself to other people.”

“…I think you need to be more informed there, because they’re generally fighting cancer, in my mind, so they’re rushing to get the cancer out, which is not a bad thing, but they need to look at other aspects also. After we get this cancer out, this patient still has a life to live, so they need the best results we can give. So if we can work with someone else to do these surgeries, to get a better outcome, but take an extra two hours to speak to them and give them the resources to make that decision.”

“… Now I would say do it. I would say something about comparing my mother’s level of self-esteem as compared to my self-esteem or my sister’s self-esteem. My sister is also been a breast cancer patient too and I think my mother has kinda lived in, she quit doing everything after she had her surgeries, she was very active but she yes, my well, she quit doing everything. She had two boyfriends, she’s very cute but she always felt like her clothes didn’t fit right, she gained a good bit of weight. She quit exercising. Stuff like that that… I think if she had had reconstruction she would have been. I mean, she never wore a swimming suit again… If she had reconstruction I think she would have had better self-esteem… I think the comparison to my mother, to myself and my sister shows the impact of beauty on a woman. I think most her daughter and my daughter would choose our same paths because I think they think we feel good about ourselves. And that allows you to go on and live life and be done with it.”

“…And to a woman, don’t settle; go to the point that you want to go back to and don’t settle for anything less. Don’t let someone tell you when you had cancer so you can’t do this or you won’t look like this … I mean don’t.”

“I would want to let the patient know that they have options and don’t listen to the first person that you go to. Do a little bit of homework and try to find a doctor who is willing to listen to you, because your outcome can be a very positive that you are gonna be happy with, if you go to the right person. I’m sure that everyone that has this procedure done, I would hope that other patients would be able to come out and say, ‘hey this is who you need to go to, this is my experience with it, I had a positive one, so hopefully you guys can’.”

J. What would you say to physicians about their role in the breast reconstruction experience?

“The biggest statements I would make would be to the physicians. Let the women know everything that she needs to know in order to get her back to the point to where she has her life back. That’s huge…”

“… the whole thing, the whole process, up until Dr. Maxwell was, ‘it’s just a breast… it’s psychological also. It’s not just physical cosmetic; there’s more to it than that…”
“... For physicians, I would say listen, listen to women. Men don’t listen to women as well as they should, especially if it’s a male physician... give ’em more options, choices, don’t demand and just give ’em choices. Anything that’s out there, if you can’t, if the physician can’t... send them to somebody that can...”

“... As for the doctors, I would really hope that they could learn about the different techniques and tell their patients about them. Get more educated on what people are doing and not fall into a rut of, this is how we’ve done it for 20 years, because times are different and women have changed.”
Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process
SECTION II-A

Sections Two A and B are the responses of women that have not faced breast cancer and do not have a known high risk for the disease. These responses are broken into two sections, the first representing direct quotes that support the underlying themes of this study, and the second representing the actual dialogue between women as they explore concepts of beauty and sexuality, and the impact disease can have on both.

Interviews

A. Familiarity with Breast Cancer

1. Do you know anyone that has or had breast cancer?

"... women who had cancer must say, ‘when do I quit looking over my shoulder? That five years seems so arbitrary, but it’s thrown out everywhere, isn’t it? Five years’ survival, five years’ survival, five years’ survival. In five years, I can worry about my hair? In five years, I can worry about my aesthetic? In five years, I can do something for myself, other than hope that I live?"

“The only person I know who had breast cancer is a man.”

“Yes, I have. I had an aunt, not related to me, but an aunt who had breast cancer. I also had a family friend who has battled with breast cancer numerous times.”
“Yes I have. No one in my family, thank goodness, but a few family friends and in-laws, family through marriage.”

“I have known several people who have gone through breast cancer. Actually my father-in-law went through breast cancer.”

“Yes, several, but nothing real close to them to know all the details.”

“My sister-in-law has had breast cancer; however, she lives four hours away, so I don’t know a lot about the process, because I wasn’t there with her. I did, however, visit with her back about several months ago, and she was extremely pleased with her new breasts, because she had full mastectomies, was obese prior to the cancer surgery, and was really surprised with the appearance of her new breasts.”

“My aunt had breast cancer. I remember I was in my 20s. She was so sick. She died from it when I was 22...”

“I am starting to realize that you do get your body back (after pregnancy) It did not feel that way when I had my first breakdown (laughter). .. I went shopping. I started realizing that I will never look the same, my hips will never be the same, and I am past that. The truth is yes, my anxiety is way lessened since I realized I am going to get it back and it is clearly not the case with reconstruction.”

“I think she became very isolated. I think she felt rejected by my grandfather because she did not feel whole. My other grandmother was completely the opposite. She had an attitude of well you are right, I am not having any more babies, I do not need to nurse any babies and let’s get this done.”

“... actually just thought of somebody else because he does not ever come to mind because he is a man, neighbor, good friend, eight years ago, battled breast cancer. It was something, I have seen him without a shirt on, it was not a major thing and he still has his nipple and I think there is maybe a scar...

“... I have not...”

“... I do have some friends here locally and I know of an aunt of a very good friend of mine. It has never touched my immediate family, that particular cancer anyway...”

“... Mother went through an experience with post-menopausal breast cancer, a handful of years ago...”

“... I have one friend that I know, and I’ve only been peripherally involved, who is a young, pre-menopausal woman, 30’s, who was diagnosed with breast cancer...”

“... she was 40. She found out she had breast cancer in one breast and they went in and took the cancer out pretty quickly, the tumor out pretty quickly”
“... yes, two... I was so young when I, when I knew... under ten years old. But I watched the, the realization, then I watched the fight. And it was, it was very obvious that they had so much left to fight for...”

“... Yes, she had a double mastectomy the first time she had cancer, and then she had a reconstruction and then it came back.”

“... and it was interesting to see how she went through it, particularly because of course, they’re well educated, and my father is also a physician, and when my mother was diagnosed, they, and I think she had gotten one routinely like they expected, and then you miss a year, then you miss you, and every time she got one, they told her, oh you’re fibrocystic, and your breasts are small anyway; you can’t really tell anything, but thanks for showing up, and so I think she sort of let it lapse, because maybe she decided it wasn’t that important, and so finally when she went back, because she knew it had been, I can’t remember, maybe one or two years, it wasn’t really much longer than that, and she got one, and they found a lesion that was right around a centimeter.”

“I don’t know exactly how she was diagnosed, because I wasn’t intimately involved. I only heard after the fact that she was diagnosed, and then I didn’t see her for a number of months, and it may have even been a year, and I ran into her coincidentally, and she was going through the process of chemo, and her hormones were out of whack, and this is a very strong powerful woman lawyer... knowing the statistics and knowing the right thing to do and knowing the guidelines is not enough...”

“She is just faking it until she gets through it... It has to impact her because that then impacts the people around her, her immediate family, her extended family, her friends. She is going to start to isolate, I think. I saw my grandmother go through very deep depression times. Unfortunately, I was not as close to her as I was my maternal grandmother who called me into the bathroom and said ‘I need you to look at my breast.’ On my dad’s side, it was very taboo. We did not talk about it. We did not use that word breast in front of mixed company. She ended up committing suicide.”

2. Have you seen the results of breast reconstruction? How did it appear to you, or how would you imagine the visual results to appear?

_Respondents reported a wide range of views from the perception that the visual results would be greatly disappointing to the expectation that breast reconstruction would look like breast augmentation. This provides an interesting view of the general public’s perception of breast reconstruction._

“... they’ve had an augmentation, so they would feel if they can do that, why can’t they make it perfect again.”

“I have not.”

“I imagine it’s probably only looks good under clothes.”

“I imagine a lot of scarring, a lot of lumps and bumps. I imagine any, any implant doesn’t’ look normal, cause I have seen the scars from any regular implant, but that tissue has been so
manipulated and so damaged anyway, I can’t imagine that it looks anything like it would have before.”

“No, I guess not.”

“I’ve seen breast reconstruction twice... the scars were horrific.”

“They came vertical from the chest wall to the nipple, from the nipple underneath and then from under the arm. I mean it was like an “x.” I mean, the scars were just very massive in both incidents. And both of these women were extremely large women. I don’t know how to describe it, large, large breasts....”

“No, I have not, I have not.”

“... I think of a tennis ball. You would think it would only be like a tennis ball and great cleavage. You recognize it from a mile away. Kind of the headlight look that you used to see with breast augmentation... Just like the disks with the model type of look, but I do not think that is the case anymore. I think they have come a long way that is not just like pucks. It more of a softer look, but I am still stuck in that kind of tennis ball look, which is a very firm like and perky.”

“Well, when we first were looking at pictures, it was pretty scary on the internet, all of the different pictures were shown of women who did not have very good outcomes, or didn’t even go through the procedure. When we looked at Maxwell’s webpage of the women who went through there, I thought it looked amazing...”

“Lots of different scars, sometimes there was no nipple, not uniform, and like indents, not what you would want your breasts to be looking like...”

“The image in my mind is pain... I’m thinking more of the actual surgery itself, and then the reconstruction, I would imagine that would involve a good bit of pain just dealing with any other arm area. To me, reconstruction in my mind, I don’t know. A big question mark, because I have not looked a lot into it, and I tend to be a little bit visual...”

“Only two. I am talking physically. Other than them, I have seen them on the internet. I have seen them on documentaries... Well on the internet, they can go from bad to incredible to worse. It is scary. They are very scary...”

“I have not. Well, I take that back. Years ago, this friend of mine whose aunt went through it, but I was in elementary school, maybe middle school. This very good friend of mine’s aunt was going through it and this friend of mine was just upset. So, the aunt came in and showed her the scar. I can remember that. It was very traumatic. Since then, I have not seen. This was probably 35 years ago. I am hoping that things have changed from that perspective of what used to be... the perspective from that was that they just kind of went in and lopped it off. I think they have come a little bit, from there but I do not know for sure...”

“... I do not know how they remove the breast tissue. I do not know what kind of scar because it is not anything you ever see. I do know people who have dear friends who have been there holding their hand, but just in watching TV, movies, and that kind of thing, it apparently can be devastatingly scarring and just kind of a huge...”
“I have, in literature, in medical literature, and it’s interesting, even before, I’m trying to think of where I was in my medical career...”

“What I’ve seen and what I know and maybe what I don’t know about the alternatives, it’s not as natural-looking; it’s not as natural-feeling; it’s not as good, and they have to get, to get that kind of mucosal tissue, they have to go other places in the body...”

“...When my sister went through it, she was very scared, and she did lots of research on the internet, which depressed her even more. When she thought she had found a doctor that was going to be able to meet her needs, that doctor did not really follow through. When she called and asked some in-depth questions on what she was going to look like, they couldn’t give her that. They told her it would be better just to save her life and don’t be picky. And that is not what I would want anyone to go through, myself or anyone else. And if it wasn’t for her determination to find the doctor that was going to give her her life back, I don’t know that she would have went through with it...”

“... I don’t deal with it routinely and directly, but let me answer it in a general sense when anyone is faced with a medical diagnosis, either unsavory or hard to digest or complicated or beyond the realm. I think you really have to first reach a level of understanding. You have to understand. You have to have somebody communicate with you on a level that you’re gonna understand. And you also have to have somebody who is gonna consider the emotional aspects, ‘cause they’re just as important as the practical ones at the end of the day, and particularly for women, we can’t separate the two. And I think personally that’s part of the reason God gave us the breasts and the uterus is because we can preserve our needs, and we can’t separate the two, and we don’t think about how practical it is to get pregnant and to breastfeed, and we just do it, because it’s the emotion, and it’s there, and it’s the love, and it’s the passion, and it’s who we are, and it’s wonderful, and it’s amazing. But we can’t separate the two, and I think when we do, we do women a great disservice...”

3. What would your expectations be if you had breast reconstruction?

_Sadly, based on statistics, a number of the women interviewed in this section will one day face breast cancer, and more will know a woman who will. This study presents a critical question regarding the treatment choices of women who face such a diagnosis: If women believe self-perceived beauty is a critical component in their quality of life, will they choose less aggressive treatment options if they feel the visual outcome, resulting from aggressive methods, will be dissatisfactory?_
64% OF THE RESPONDENTS REPORTED HAVING A NEGATIVE IMPRESSION OF THE VISUAL OUTCOME OF BREAST RECONSTRUCTION.

4. **How would you expect your breasts to look after breast reconstruction?**

“It would look at least the same, but probably a little bigger, because I am not very big. I may as well enhance it a little bit. I used to be bigger before three children.”

“... I guess it would because it would be different than I was before, but I would be happy with it looking like it did before.”

“Yes, I do believe that it can (look like augmentation?)... just looking from you and seeing my daughter with a bathing suit top on, I see similarities.”

“It should be able to look like augmentation.”

(So your visual expectations of a breast reconstruction are that you would come through it with pretty sexy breasts...) “Yes, absolutely.”

“I don’t know that I had any expectation either way, knowing either way. So seeing it, I do think it’s pretty amazing, and seeing some of the pictures on Dr. Maxwell’s website, I thought were very amazing, and the before and after when women had botched jobs and went to him, and there was just a night and day difference...”

“... it is so important to pick the right doctor for reconstruction, minimal scarring if possible, the right nipple placement is very important. I am a D right now. I would not have to be an E when I was reconstructed. I would be happy with a C. They need to be natural looking. I do not want to look like a model in a magazine. I just want to look like me...”

“Honestly, I would expect to have to settle for whatever they could do and then if I wanted it to be fixed the right way to have to go somewhere else...”
(And what do you think the average person’s perception of the results you’ve seen with Dr. Maxwell’s work would be? Do you think they would consider them, on a scale of 1 to 10?)

“I think they would probably, if they had taken time to look at the other options out there, they would give it a 12, because they wouldn’t have even had expectations that high.”

“...I will do as little as I can at first, whereas when you first hear like if you have the gene or if you have a lump, just take them off because you can just have them put back on again. Well, you cannot.”

“I’ve never had any type of surgery, so to think that something might be removed would probably make me feel very uncomfortable, and I’m the type of person I want to put things back the way they were before the problem occurred. So I think I would want to have my breasts looking the way they did before I had them removed...”

B. Women and Their Views on Beauty

1. How important do you think an optimal visual outcome in breast reconstruction would be to the healing process?

Similar to the responses of the patient population, non patients ranked a feeling of self-perceived beauty to be critical to the healing process. For most women, this element is identified as fundamental to their sense of wellbeing, an essential component of self-confidence, and as having direct impact on their quality of life. Patients and non patients, alike, view the need for self-perceived beauty as a core element of feminine nature.
ALL RESPONDENTS REPORTED THAT A SELF PERCEIVED SENSE OF BEAUTY AFTER BREAST RECONSTRUCTION WOULD BE A CRITICAL ELEMENT WHEN CONSIDERING HEALING FROM THE TRAUMA OF BREAST CANCER.

“I think it’s a lot more tied to the core essence of a woman... think that it gets brushed off easily by saying, ‘oh it’s just vanity’, and I think that is the barrier that this work is seeking to overcome is that this isn’t about vanity it’s about victory. And I think what is easily dismissed when you’re speaking to those in the medical profession, that will want to downplay the issue of the visual outcome, is that it is an amputation. It is an amputation of a sexual body part and so that is a very important statement. I mean even with testicular cancer they have implants that replace the physical look so clearly our sexual parts are extremely important to our self-esteem right, that it whatever type of woman you are that's totally an individual decision but if you’re a woman who needs that level of visual outcome that the resources should be made available to you.”

“I look down at my chest and I thought if I did not have, I do not have big ones, but if I did not have them, I completely would think about my outfits I choose. What would it be like then?”

“And you don’t need them like you do an erection, it’s not necessary to procreate, it’s not necessary for pleasure, but it helps... And well, I think that’s where men come from, and I think women accept it because, yeah, you’re kinda right, it’s not, it’s not necessary...”

“That I have a choice and that I have hope. This is not out of their control. Does being whole in the end help that part of that hope? That is part of that hope that you are going to get me back to where or at least as close to back to where I was before this all started. It is a journey. It not just like going in and having your appendix out...”

“... it goes back to that, is it just a breast or is it part of your whole being. It is part of your whole being. Billions of dollars are spent every year with women getting breast augmentation...”

“... women, at some point, think, ‘I just need to be happy with this or people are going to think it is
all about the look of my breasts as opposed to surviving this cancer’, and if you have a doctor saying that to you…”

“... I mean, I think it’s huge, and everybody remembers when they are a little girl, and they wonder, ‘when is it gonna happen? When am I gonna get them? Am I ever gonna get them? I’m not sure; my mom has them.’ You think of this and in this country overwhelmingly, the aesthetic is very important, and that’s a part of it. It’s the overall aesthetic that’s important, and you have to find a way to feel good about who you are.”

“I would never want to lose that pride of being a survivor. That is a huge amount of pride. I go to the doctor and I have a clean report, and I am like yes! I am proud. So I would be very, very, very proud of being a survivor, but I think that there is a time and a place for that. I think I would be the kind of person who says, ‘well that is behind me and I want to really feel confident and beautiful.’ I cannot imagine what I would do if I was completely without my breasts.”

“I think it’s a woman’s choice, and personally, I think if a woman wants to improve her look by whatever means she chooses or she can afford, I think she should. And if plastic surgery is one of them, then I do, for a fact, know that it has made me feel better about myself when I started aging and had plastic surgery…”

“... I have family members who have had plastic surgery, mainly breast reconstruction, augmentation, and my mom had a facelift, my oldest daughter had a facelift, and my daughter had a nose job… it is not tremendously invasive, and typically there’s a smaller recuperation time, and usually the results are pretty amazing.”

“... I think if it was a type of reconstruction, I would be open to it. To have things done cosmetically, I probably would not, mainly because my husband’s seven years older than me, and he looks it, and I don’t want to look like his daughter.”

“If you’d asked me this question 15 years ago, I’d probably have a different answer than I have today. Then I would have said I see it as superficial, but now, having been knocked around a little bit in life, I think whatever someone needs in order to feel the best about themselves is… it’s really nobody’s business but their own…”

“... I understand that the human body is the human body. They cannot control everything that happens. I would expect to pick the best person that I could and trust that whatever they have done is the best that they could do... I would expect to get information beforehand about what they think would happen. I would not expect what happened to deviate much from that, unless something drastic happened. I would expect an explanation if it was very different. I would expect to be able to be told what would likely happen and make a decision based on that information…”

“... specially being able to save the nipple I think is an amazing type of surgery, and it was… I think that the results were very good…”

“... I think it’s very important myself. I’m not as concerned about the physical appearance as I am with the mental and emotional appearance of a person; however, being married to a younger man, twelve years younger than I, it would be very important to me to make sure that I had the best options to becoming more physically appealing after a mastectomy…”
“...it matters how you feel about yourself and your inner beauty carries out to how you look and what your vibe is that you give off. That adds to your beauty...”

“I think that it is a fine line between being a want versus a need, but I think going through that kind of situation, you would need it. It would be a need for your soul almost to help you heal and just to make yourself feel like you...”

“God created us in his own image, both male and female. So, if part of us is missing, then we do not feel whole. Without it we do not feel like we are in a complete mix. That does not mean that he loves us any less, but we still want to feel whole. I think for women too, it would separate us from our femininity..."

“....With my mother, we immediately went to the doctor. His point of view was we will do a full mastectomy, you are not childbearing. Well, she was not childbearing, but she has a husband. Yes, she was in her 60s, but she was still a woman. Our breasts are what make part of us. I think that the women that I have encountered, it is a very hard journey for them and they had to have a good support system to come along beside them and say this is going to be okay. Just to get to the surgery to just get past the cancer, is a whole separate issue. Then to get into you are looking at you again and you are wearing bagging T-shirts or stuff that is loose fitting instead of a cute top on a summer night. Women compare themselves to other women all the time. That just comes naturally. It do not matter if you are 16, 26, 46 or 66. We as women compare ourselves to other women. When you are sitting there at a dinner table or at lunch, and everybody is dressed up really cute, and as a breast cancer survivor, you are in a baggy T-shirt, that is still a mind game. That is what I hear a lot from women that part of me is gone.”

2. **Do you think having confidence in your physical appearance has a significant impact on your quality of life?**

“I think it’s very important. I think it’s, it’s one of those things that’ll you’ll never be the same, so let’s get it close to the same as possible.”

“... It should be a very, very high priority for them, because it’s your self-image. It’s one thing to survive it, but to survive it with fewer scars, I think would go a long way to healing as opposed to looking down and having that constant reminder day in and day out...”

“It assumes a lot... If you put your mind to it... truly, if you feel positive, I mean it is as simple as when you feel happy, you breathe more deeply. When you breathe more deeply, you get more oxygen. When you get more oxygen, your blood is healthier. It is as simple as that. Whenever you rely on your secondary muscles to breathe, what you are doing is really you are creating a lot of rushing hormones to your body that do not do any good for you. So yes, that was the mindset I was coming from, but when you are positive thinking, gosh it is huge. I really do...”

“It's very important... just slacking off in physical appearance in the last 18 months... I have not been taking care of myself like I used to... I feel a lot less confident, and that lack of... not wanting to stick my chin up, my head held high as much. More of a tendency to settle for whatever it is...”

“A lot more optimistic... just a lot more positive. I felt during the time my mom was going through her healthcare issue, I had small children, and I was just pulled, and the number one thing I did
was physically take care of myself, and I don’t know if I could have pulled off what I pulled off had I not been in the best shape of my life at that point.”

“Absolutely... I think your self-esteem can make or break everything you do. It affects your mood, it affects your health, it affects your job, it affects your income. I mean, if you do not like you, other people cannot.”

“Having reconstructive facial surgery has impacted me. So, I am scared. He assures me it will be positive and I will be happy with it, but only I can know what I am happy with. I do not care if scientifically it looks better. I wanted to still look like me and still like the person people I care about love. It is important to me...”

“You kind of go to the vanity where you want to look pretty. (What is vanity? Is that a word we have been taught?) I am sure it is. What you think about your looks and how you are. I think there is probably, with some people, there is some guilt for thinking about how you look, that that is so important because they all say it is on the inside that counts...”

“That is huge. I am a personal trainer, so that is definitely clearly a big deal to me. Oh gosh, it is huge. Huge. That is huge. It is on my mind every single day...”

“Well I can say for myself growing up literally from the gate, I was very confident. I had no comparison. I had beautiful friends and I was not ever comparing. I was not asked to dances very first, but I just felt really pretty...”

“... I do not want to say being beautiful to me means like showing off your body, but it definitely means working it. That is huge. Femininity and embracing your curves and your body is a personal decision, but I am proud. I feel like everyone should be proud. I think that there is nothing wrong with that...”

“... we are very blessed. Men are so lucky. I think you have to rock it, I do. I think that in a post cancer treatment kind of situation or setting, I thought about this last night a lot. I actually talked to my husband about it. I said, ‘how would you feel if I had a mastectomy or double mastectomy, what would you think? Would you want me to get anything redone?’ He said he really did not know how to answer it. I said, ‘you are not going to offend me if you say you are with me for any reason other than my amazing mind.’ He laughed and he said, ‘well, you obviously have to make the smartest, safest decision.’ He said, ‘I love your body and I would want you to feel proud and happy.’ That is more important to him because he knows that he has a better wife when I am proud and happy. When I strut around and I feel good in my heels, I am a little more fun than you might figure. I really am. So, he knows it means more to me than maybe even I let on to. He says ‘I would want you to be proud and happy because that is when I love you most and that is how I love you.’ It is funny. I think the right answer is I would want what you would want and nothing more, nothing less. I think he knows what I want is to feel completely feminine...”

“I wouldn’t even call it visual... it’s not visual... Not to me, it’s because I don’t’ know, it’s, I know... that’s probably the best word to describe it, but it’s not, it’s a feeling. It’s a sensation.”

“All the time...”
“This might sound conceited. I have always been considered attractive. To lose that, not that it would be my face, but is always has been kind of been a package deal. I have always had a cute figure. To lose part of that, again it is losing an arm. It would be drastically changing. That would be a hard step out into the world totally different…”

“It does. It does, yes…”

“Oh yes. I believe that your mind and your emotional state play a critical role in how you handle it and how you get through it…”

“Yes.”

“I think that women in general, if they’re not feeling good about themselves, get into kind of a depression or a ‘not ready to move forward’ type of state, and it could inhibit healing tremendously.”

“It starts at a very young age when you’re in middle school now, to where you’re condemned for any little thing, and you’ve got the media that tells you you’re supposed to look a certain way… I don’t know the answer to how you get past all of that, to be able to have a strong enough self-esteem that it is not influenced by the world in general, what the world’s expectation of what a woman is supposed to look like, what men tell you is their expectation. So it affects a woman a lot on how she looks and how people perceive her…”

“… I mean, think about those times, like when I have five extra pounds. I honestly don’t think anyone would ever know, but I know, and I know when I’m doing what I need to do to exercise and take care of myself, and I know the difference, but other people they say, ‘You’re fine, what are you complaining about? You’re skinny.’ And I’m like, ‘but I’m not me’…”

C. Sexuality

1. How does your body confidence affect your sexuality?

All respondents reported that self-confidence plays a direct role in their sexual relationships.

All respondents reported that satisfaction with their appearance played a key role in self-confidence.

“Breasts are involved in sex. That is a huge part of most peoples’ lives. I think that would be relevant there. I would say rocking it would be a little more of that third revolution, which is really saying ‘I am sexy, I am a woman and you should love me.’ I think that knowing these options, women are going to feel a lot less like just a statistic and more like a survivor because they are saying, ‘look at me, I have been through this and I have bounced out of it. Now I am back into my femininity versus I am a survivor. That is why I look like this’.”

“I want to say, not to be too dramatic, I think it is an eight to 8 ½, maybe nine.”

“I think intimacy and communication kind of go hand in hand. So if we are not intimate, communication is not as meaningful or something.”
“.... In this interview, I started thinking what would it be like the night before a surgery? Like looking at them for the last time would be like they are not going to be the same. That is huge. I would definitely break down. It is a relationship you have with your body from puberty and the definitely into like your sexual adulthood and then it is like your last night with them is really odd I am sure...”

I think it’s extremely important, “ No one wants to be making love when they don’t feel good about themselves...”

“I think it’s very important on how you look at yourself, because if you are unhappy with either internally or externally, that puts a damper on everything...”

“Oh, I mean, you feel more confident in that area, absolutely...”

“It would probably take a lot of coaxing on his part because she would always be self-conscious. I think you would be very self-conscious about how you looked. You would want to hide or wear something over it.”

“So, it is difficult enough when strangers are looking at you weird if you have lost a limb or you have some kind of malformation. When it is the more important person in your life, and yourself looking back in the mirror and not liking what you see, that is huge...”

“You would almost be going through the motions because you felt like you have to do this, but you so would not be there in your head. You just would not be there.”

“Not having it would mean never taking your clothes off again, not feeling sexual, and we are sexual beings.”

“It is probably 90% of it.”

“Yeah, I can’t feel good unless I look good, and that’s whether I’m clothes on or clothes off...”

“I don’t have a problem walking around naked now, and I don’t see that I would, being happy with the results that I’ve seen in you.”

“We are sexual beings. I have been happily married for almost 25 years. It is part of your entire being. To lose that part of it, and even like you were saying with reconstructive, if it is a kind of hit and miss and if you do not have access to specific things, even the reconstructive sounds like maybe it is not quite as great. Some people maybe think it is. I kind of thought it was. I was picturing it to be more if you were going from nothing to reconstructive, I was thinking more augmentation.”

2. What is your perception of what your spouse’s reaction would be if you had breast reconstruction?

“He just expects it to be okay that she is happy that she is alive. He is not allowed to have an opinion on how he thinks she looks...”
“I would hope he would have someone he could talk to about it because people feel like you are not supposed to talk to the person who has had that done. I think there is a lot of carrying it on your own when you are the spouse…”

“… I think the brain is a huge part of it, and I think it’s your perception; it’s your perception of your spouse’s expectations; it’s your perception of society’s expectations, and it’s your own personal demand on yourself; it’s what you expect of yourself in terms of how you see achievement…”

“… because if I’m happier with me, then he’s happier with me…”

3. **How important do you think it would be to include the male voice?**

“I am processing it more because I think it would be very difficult to get men to want to stand up and say, ‘yes I care what it looks like’, because I feel like they have been so groomed and trained to just care that the woman is alive and safe and cancer free. I think it would be very difficult to find men that would be willing to be part of the voice to say that it is important to maintain and aesthetic… She would have to make him, because he would look like some sort of creep to stand up and say that.”

“I think the woman have to do it for them though too. It is probably a lot of pain and trials to go through, no pun intended, and the women have to want it for themselves as much as the man has to care.”

“I mentioned your former point earlier, when I think it is something the woman has to give to herself, but to the latter point, I think the woman has to convince the man to speak out if he needs to or if you want them to.”

D. **Education and Awareness**

1. **What are the best ways to ensure women know their options in breast reconstruction?**

“Doctors are required to get patient consent if they are going to use their data for a clinical trial or use any of their specimens or tissue. If you really want to make this happen through the Medicare program and through the new Federal Department of Health Insurance, you can require physicians to disclose on a piece of paper signed by the patient that the patient has been told their options…”

“… If the majority is not capable of helping themselves through the process, who is their mentor or surrogate helping them? Is it a care navigator at their insurance company? Is it their primary care physician that they should go to? They need terminology and education. It could be all of the above and for each person it may be their mother, a friend, but I think that anyone going through that type of trauma needs a mentor…”

“I would be more worried about reaching them at their gynecologist’s office, educating gynecologists who are making that initial referral to make sure that if there is a pamphlet or
something they can give them about, getting people to ask the questions. I do not think you are going to reach every doctor…”

“… Every breast surgeon obviously has their own opinions and their own thoughts about how they want to do things. But it is just educating people enough to argue and push for what they want. I would do that in the beginning…”

“… I am a human being, just as you are a human being... we are very fallible but very human, have emotions and to give the absolute best quality of care and be real honest and humble if you don't know something…”

“I don’t know, I'm always on the internet, so anything that lands on front page. The Atlantic is very good, I think it has a very young, powerful readership. They have a great mobile app, I think, social media. I mean if I hopped on Face book right now and said ‘Look, it doesn't have to be this way, read about this. I don't know, it’s, breasts are so taboo anyway, especially on our conservative East Coast. I mean, I think I would start with a metro billboard, I see those every day. I think the rallies and the political stuff, for people like me, it just gets lost in the hum of all the others. I think if you wanted to do a public thing, it’s gonna have to be outreach to the public and not just the people that care about it because they already care about it for a reason.”

“I think giving pricing options is as important as giving risk options once you start talking about reconstruction. People care so much about what things cost. I think being able to say this is what it will take. It is sad, but people sometimes put their pocketbook above their health. I think that is important.”

“On the internet, I would be posting it on Facebook, that whole hey does anybody know? Have you gone through this? Message me. I would be reaching out in social media like crazy. I would be out there. I am not one that sits in a room and does not say anything.”

“Well, I used to go to a male internist many years ago, but then I realized that I did not feel as comfortable that sharing certain things with the physician as if I would with a woman. So, I switched to an all-woman primary care practice called the Cameron Group. They are in Silver Spring. They are mostly women who are affiliated with the George Washington teaching hospital here. Even if my primary care physician is not available, I always get a woman. I found that to be very reassuring that how I communicate my words, I feel like they are doing a better job. My obstetrician is a woman. My gynecologist is a woman. I just have more difficulty being intimate about things with a man who is not my husband. I just prefer that. In fact, my doctor is my age. She is probably five years older, but I like that as well because she is experiencing things ahead of me and can speak with first-hand knowledge about whether it is menopause or work life balance. I just feel like I am talking to someone who has a personal frame of reference, not just a medical degree.”

“I do think that whether it is Wikipedia or as I said Web M.D., I think when you put in the words breast reconstruction, and you may want to get, there are a couple of very talented social media experts. So when you typed in breast reconstruction, it can automatically go to nipple-sparing.”

“Well, I have a close friend who’s a surgeon, a plastic surgeon, and he does extensive research in other areas of medical information that I need. I would start with him first in my options and where
to go, because he does research for me out of Europe on other things, so I just wouldn’t go to one source.”

“I would look to other people’s experiences, statistical facts, compare those, try to talk to people themselves that would allow me to speak to them about their experiences, treatment and research and support and lots of variables.”

“... since you went through that, I would probably come to you as the most knowledgeable person, and if I had a friend who suddenly found out they had it, I would be sending them your way for advice... That probably would have been the first thing that came to my mind.”

“... I’d begin like everybody else and Google it... and I also know that one of those first two answers usually that come up that are highlighted in yellow or, so I tend to skip those...”

“... don’t accept the first answer as the final word and look for other... get second opinions. That would be the biggest thing, and I’m trying to put myself in those shoes, but other than that, I would feel a little bit overwhelmed...”

“... I think I would use three resources. I discuss it first off. Of course, the main goal for me would be to get the cancer under control. I would start here locally, maybe with a clinic or M. D. Anderson. I think I would talk to a female oncologist because she could relate better with what I was going through as a woman. For a man, they are not going to relate to it as well. I just think, unless they are very, very compassionate, the doctor. I would certainly use the clinic that I was hooked up with to do my cancer surgery. Then, my second resource I guess would be to search the internet for support groups or foundations or companies out there and kind of investigate it a little bit on my own to see what is out there. Of course the third would be I am real big on referral. If I found the surgeon to do it, whether it is here locally or I had to fly to Texas, California or New York, I want the best one. I do not want a botched surgery. Then I would want to talk to at least five to six patients that they have done this on. So, it is a time consuming process...”

“... to some extent, it is not the doctor’s fault. At some point, the patient has to see for themselves. We cannot expect the doctor to feed you and baby you. You have to be responsible for yourself...”

“... Yes, and that the internet would be the first usual course somebody’s gonna look, whether it is that person or a family member on their behalf. That’s the first place they say they’re gonna look.”

2. Where would you seek information regarding breast reconstruction?
GRAPH #27: SPECIALTY AREA FIRST SOUGHT FOR INFORMATION REGARDING BREAST CANCER

100% of respondents reported that they would seek information from their gynecologists in the event of a concern with a lump, concern with breast cancer or a breast cancer diagnosis.

Patients, having undergone breast cancer, reported that their gynecologists were a primary source sought for information, but that this specialty area was not able to provide adequate information.

GRAPH #28: SOURCES OF INFORMATION FOR BREAST RECONSTRUCTION

50% of respondents reported the internet as the primary resource they would rely on for information regarding breast reconstruction.

3. In the event of a breast cancer diagnosis, what would you expect from your diagnosing physician?
“I am just concerned of being told that I am wrong, of my opinion not mattering because I am not a physician, I am not an expert. I am not the one. My opinion may not be as important as his. It is more important to him to be perfect and do a perfect job than my happiness with the outcome...”

“... I think doctors are perfectionists... I think it is both absolutely, being able to tell that someone is good at what they do and they do not come tell me how to do my job. So, I feel uncomfortable sometimes trying to tell them how to do theirs...”

“... we are coming from an area where you’re told accept what somebody tells just because they are supposed to be the expert. We all do that a lot. We listen to somebody who is supposed to be in charge, who is supposed to know what they are doing. That is why we go to them. You take that and you are supposed to be able to trust that.”

“We are always relying on somebody else to know what is best. I think that is one of reasons why it hit me so hard was because there are people, including myself, who would have at one time said, ‘Well, I guess that is okay if that is all I can expect, if that is what is going to happen, if this how you do it and this is how it is done.’ If that is what you expect and you settle because they are supposed to be the expert, then you would not go looking for something else, unless you come along somebody like you, or maybe not even quite as knowledgeable, and you say, ‘Well did you ask him this that and the other?’ And well, no we did not. Then maybe you would find out that there are other things and maybe you might ask a question where it would not be so easy for you to get stonewalled and accepting what they gave you...”

“We are already feeling guilty for asking.”

“...The one thing I would want to say when I think about this is patients really have to be demanding... I’d like to say that every physician is gonna try and address that and try and sort that out, and I’d like to say that every patient is gonna appreciate that when you do, but at the end of the day, I really think you have to not be afraid to take a stand and say, ‘I know what your literature says, but this is me, and I know me, and how do you translate it to me?’”

“... First, they need to put themselves in our shoes. Put yourself in my position for a moment. I am not just another case number. You may have a 100 patients that you have seen today, but I have a name, I have children, I have a husband, I have a family. I think when you took your oath to become a physician, you took on a responsibility that you owe it to your patients to give them all of the options out there that are available to them, and then let me make in what is my opinion best for me and my situation, because no two people are alike. No two situations are alike. No two cancers are alike. If my husband had had this done two years ago instead of playing around with this nose surgery two or three times and we had not been so proactive, I feel like he would not be alive in five years because it would have hit his brain or his lungs. A girl had called me the night before and she just told me that I have squamous cell in my lung and they have given me six months. She had had a piece removed. I just think that that was one of those God things that he would say, ‘Open your eyes; fight for your husband.’ Had we not pushed a little harder, doctors are just like okay, I have 100 patients today, I am going to be here four hours in the office, how many minutes can I spend in each room?”

“As a physician, I hope that you would put that aside and imagine, assume I am your spouse or your parent, and treat me as though I was your spouse, your daughter, your mother.”
“A great deal of ethical responsibility. I would imagine that the reality of that is that there are none currently, but I think they ought to be held to a much higher standard, especially when dealing with… because breast cancer is so prevalent, in dealing with reconstructive surgery. It ought to be part of the complete package and part of what’s required of someone who is in a specialty… an oncologist. I think they should be required to have a wealth of information for women post-operatively as well as… I mean, not just immediately post-operatively, but long-term as well…”

4. What would you say to a woman who is diagnosed with breast cancer?

“That there is hope, and that they can feel like themselves again, sometime in the future, after they’ve gone through the journey they’re gonna get ready to go through. That they can feel whole again, that they can look in the mirror and feel like themselves…”

“… Women need to protect themselves, because no one else will. They need to stand up for themselves, because you’re the only one that can make sure that you get the response to the answers to the questions yourself by asking them…”

“No one is gonna fight for you like you will for yourself.”

“I think it needs to be a whole body concept of what all happens to the body when they go through treatment, chemotherapy, radiation, and how can those also be combated… It’s gotta be, you can’t just feel good about your breasts. Your whole body has got to go through this, so you’ve got to have a full body type of knowledge of what’s gonna happen and what you can do about it.”

“The focus needs to be on you, because you are the one who needs to come through feeling good…”

“Do whatever is gonna make you feel most whole afterwards.”

“I like the choice that I would have the choice to make a decision based on what was in my best interest, and I wouldn’t automatically take the recommendation of my physician. I would again weigh it out on what I felt looked like my best interest…”

“… if you can get it into the hands of women, where they’re able to think, I know where you at least need to look for information, and we can explain something to you, or you can have better than that. If it does nothing but cause dialogue, questions, ‘cause I think a really hard lesson is, if the physician that a woman is speaking to doesn’t do it, he’s most inclined not to tell her it’s possible.”
METONYMY

Artist: Zach Lindenberg, 16, watched his mother struggle through the journey of ovarian cancer, chemo, the loss of her hair, female organs, hormones and breasts. At each juncture, he listened attentively as she described her determination to regain her physical self in every way.

In an expression of recognition, he used an impulsive photograph to create a mirror image, reflecting an interpretation of the “glass wall” society so often uses to divide a woman from herself, pre and post cancer, when, in fact, she remains the same woman.

With painful words like “We saved your life, what else do you want?” women facing cancer are often made to feel guilty for the need to feel sexy and whole after the experience.

Entitled, “Metonymy”, (when something is not called by its own name, but by the name of something intimately associated with it) it captures the truth many women feel—that they have been renamed ‘a woman who has faced cancer’, leaving behind the truth of the individual she deserves to be.

A woman’s needs do not change with a diagnosis—what changes is the journey she will undertake to meet them.
SECTION II-B

Section Two B introduces the actual dialogue between the interviewer and respondents as, together, they explore the relationship women have with their bodies in both health and disease. The respondents in this section are non-patients, and, as such, express high expectations on the extent of the communication process anticipated between physicians and patients, and reveal the important role self-perceived beauty plays in confidence, sexuality and quality of life. The interviewer is a patient who has undergone a prophylactic mastectomy, and ovarian cancer.

Interviewee: ... but I think that it's easier to concede than to not, and we're our own worst critics. And I think it's huge, unfortunately, and I think some of it... I know plenty of women who are beautiful, and they don't wear makeup, and they're not slaves to fashion, and they wear whatever they want, and maybe they're perceptions of it would be different, but I still think they would want to be able to look at themselves and feel like there's a self that they know and feel like they are who they are. Women are still going to exercise and take care of their bodies, whereas you may have other people who maybe spend more time putting on makeup or spend more time thinking about fashion or will wear, like you and I are right now, high heels and not worry about it as opposed to being practical and wearing flats. I work in academics and it's funny, even on my slouchiest days, I kind of feel overdressed because a lot of women wear just clogs and tee-shirts, and that's just fine, and that's who they are, and they are okay with it. So I think there are so many different ideas about the aesthetic that you're okay with; I think it's hard to generalize it.

Interviewer: It's interesting, because I've stratified women in this work into five categories, basically looking at the importance of the visual outcome, not as a right or wrong, but as a psychological aspect of healing. You cannot actually determine who's gonna fit in what category, because one of the most beautiful photos I have is of a woman who is 5' - 5", very sharp-shouldered, slender, and she's sitting on a beach, and she's wearing a bikini bottom, and she has on no top and no breasts, and she's gorgeous. And it's immaterial that she doesn't have breasts, as she was comfortable, obviously, with that. Whereas, at the other end of the scale, you have a total girly-girl who defines herself by her curves and is extremely visually-oriented. So one of the things I've been exploring is that whether or not there is almost a reverse discrimination. If you fit on the low end of the scale, there's a lot of accommodation in current, general offerings from the medical world... but if you're really at the high end, where you're comfortable with plastic surgery -- maybe you've had breast augmentation, maybe you have a very high standard for visual outcome -- you enter into a place where you're told, “we saved your life, and it's good enough; what were you expecting, this isn't breast augmentation...” So that group is most affected by a lesser outcome, and they're almost criticized for their natural psychological construct and their need to achieve that outcome and so that's the group most likely to withdraw into a shell when they're really unhappy.

Interviewee: And you wonder what those women in the one, two, three are hiding behind. Maybe they hide behind weight, or I'm not attractive anyway, so it doesn't matter. I think there're a lot of things that keep people back from even pursuing an aesthetic. Some people
may not think it’s worth it; I think it’s the point I make. I think they may be almost worse off than the ones who are clearly and openly about the aesthetic.

Interviewer: Would that be something that would be difficult for you to deal with as a woman?

Interviewee: I mean, I would have to say yeah, but I don’t know if you can separate it from the whole emotional aspect of thinking yourself as ill and potentially, I mean, I think it would be the whole package, but yeah. I mean, once you are day to day feeling again like who you are and feeling confident, I think you sort of have this baseline that you’ve become okay with, and that’s who you are, and that’s your day-to-day confidence. Even if you don’t think about your aesthetic all the time, you sort of start from, “this is me, this is me, and this is where I’m going”, and if you have to think about something being off, whether it’s you. I mean, from something stupid to you fell and scraped your knees, and you’re wearing a skirt, and everyone can see there’s a giant scab or whatever, or you’re going to a formal, and you have a big bruise on your shoulder for whatever reason... then that affects your perception of yourself and in a way affects your confidence.

Interviewer: What’s interesting is what you just described is sort of a plus and minus balance sheet that women keep in their heads and that when there’s a deviation...

Interviewee: I mean, when you’re having an on day or an off day, whether or not it involves nipple reconstruction, you have on days and off days, and you sort of adjust your standards, and when you don’t have anything else to worry about, you might worry about stuff that’s kind of minuscule. And when you have bigger stuff to worry about, you worry on a bigger scale, or you worry on a different scale. It gives you a different perspective on what your zero is.

But I also think that we cannot separate the psychological from the physical. I think we can’t do it, and I think no matter what sort of medical problem or medical illness we’re treating, it has to be considered as well... it’s just as important as the physical. It’s the aesthetic and the emotions that may go with it, whether they have to do with aesthetics or not. The psychology of it has to be addressed as well. They cannot just address life and death.

Interviewer: I use the term a lot, “giving permission”, because women will allow permission at different levels. So okay, most women would allow themselves permission to have breasts. Some women would question their need to have beautiful breasts, and then some women would question their need to have restoration beyond their breasts. And it kind of works its way down the line. There is a reality to survivor guilt, because as you get closer to the goal, like especially if you’ve gotten past the socially acceptable box, okay you have breasts, nobody’s gonna question that; okay now you have beautiful breasts, now that’s okay, we can understand that, but now you want beautiful breasts and to be completely restored, now gee, how many women get that opportunity? There is a voice of survivor guilt that says, “Why you, why should you have so much, why do you get to live, why do you get to succeed, why do you get to go forward?” And it has been a common vein in the interview process for those that keep climbing the bar, for those that keep climbing for the next rung and the next, there is a question, there is a need for permission. And that permission scale comes along the five-year span as well -- diagnosis to okay, you’re cured. Like in year two -- I just interviewed someone the other day, two years out, who said -- is it okay yet for me to be happy, is it okay yet for me to be hopeful?
Interviewee: I am just concerned of being told that I am wrong, of my opinion not mattering because I am not a physician; I am not an expert. I am not the one. My opinion may not be as important as his. It is more important to him to be perfect and do a perfect job than my happiness with the outcome.

Interviewer: So, that is really interesting because most women do not actually realize that the oncologist actually does not remove the breast tissue. It is the breast surgeon. And the way the breast surgeon removes the breast tissue can have everything to do with what the plastic surgeon can actually do.

Interviewee: Right; and I would not have known that.

Interviewer: Most women do not. So, the breast surgeon is in a position where he decides the way the tissue is removed. It can have to do with, the thinning of the flap, making the skin too thin, or compromising other important elements for symmetry in the long run. There is a tremendous need for breast surgeons and plastic surgeons to work together very carefully.

Interviewee: I would have thought a breast surgeon was a plastic surgeon. They should not be allowed to do that if they are not a plastic surgeon. I am not letting anyone touch this who is not also a plastic surgeon.

Interviewer: Would it be your perception that you would be told of all things available even if that particular surgeon could not provide them?

Interviewee: I do not think that happens, but I would appreciate that.

Interviewer: So, that is exactly the point that it does not happen. Therefore, we need tools and awareness opportunities that make that possible for women so that they really can identify what is available even if the surgeon they have been recommended to... does not necessarily provide it.

Interviewee: At work, I do not even like when various products are not offered to me because the vendor thinks they are out of my price range, because I find it highly insulting and that is not even my health. That is printing a brochure and they say, “We did not offer you this paper because we know you like to stay within a budget.” I switched vendors for that reason at work.

Interviewer: So, informed decision making?
Interviewee: Yes, I like all the information and I may not pick that. She was right; it was out of my price range.

Interviewer: You have the right to know.

Interviewee: I left the vendor because I had the right to know.

Interviewer: It is interesting; I am sure you are familiar with informed consent in clinical trials, with the goal being that the patient has every right to know everything they need to know about a product or a possible outcome or a negative side effect.

Interviewee: The good, the bad and the ugly, and I will manage it.

Interviewer: Right, that is the informed consent behind any kind of clinical trial, but yet when we talk about an interventional treatment or a surgical intervention that is well-known and recognized, I feel we do not adequately meet the expectations of informed consent. So, the information tends to be delivered within the skill scope of the person delivering the information. Informed consent from my definition would be that you are informed of everything possible and each option that may be beneficial to you, and that you decided based on the options, not just those that are available there with that surgeon. Is that somewhat of what you are describing when you say, “I want to know everything?”

Interviewee: Correct. I think there are laws and regulations that protect clinical trial victims but do not protect people seeing a regular physician.

Interviewer: Do you think it would affect you to be uncomfortable with the visual appearance of your body, whether it is your face or your body? Do you think it would affect you in your emotional connections with people and your confidence level and your overall sense of self-esteem?

Interviewee: Absolutely. I mean, I think I would figure out how to deal with it and eventually be fine, but absolutely. I mean if you do not feel comfortable, you do not feel comfortable. You cannot do anything.

Interviewer: You cannot do anything. So, do you think that when we really struggle with an area that is affecting our self-esteem that it limits us in other areas of our lives?

Interviewee: Absolutely. I think your self-esteem can make or break everything you do.

Interviewer: It has an overall effect?

Interviewee: It does. It affects your mood, it affects your health, it affects your job; it affects your income. I mean, if you do not like you, other people cannot.

Interviewer: It is very interesting because as we go through this work, we find that couples are not really given the permission to address the impact of self-esteem after cancer, addressing body image after cancer tends to be a place that is difficult for men partners. There is a lot of
fear on the side of the male partner.

Interviewee: He just expects it to be okay that she is happy that she is alive. He is not allowed to have an opinion on how he thinks she looks.

Interviewer: How do you feel about that? When you think about the person that is important to you, would you try to look at it from his perspective, how do you feel about that?

Interviewee: I would hope he would have someone he could talk to about it because people feel like you are not supposed to talk to the person who has had that done. I think there is a lot of carrying it on your own when you are the spouse. I would feel guilty if I was disfigured. I would feel guilty that he was left with that and could not talk to me about it and had to carry that burden of trying to make me feel better about it all the time.

Interviewer: Because inside, you would know that there was something different.

Interviewee: Exactly. You would spend the rest of your life trying to ignore it and not talk about it.

Interviewer: One of the things that happen sometimes in this U.S. interview process is that people will say, "Well, there is no point in raising the bar because so many women cannot afford it."

Interviewee: I do not know; that may be true.

Interviewer: Well what is hard about it is the reverse discrimination. If you are someone who cannot afford it, should you be allowed the option or are we not supposed to improve the aesthetic outcome because there is some person in the population who cannot afford it; is it Robin Hood?

Interviewee: Do not make decisions for me about what I can and cannot afford.

Interviewer: Yes, going back to your original point.

Interviewee: The same as that. When it comes down to trials or fancy devices even, people are not given options because there is the theory that they will not be interested in them. It is not fair.

Interviewer: You are providing a really interesting other angle, which is, why are you limiting information based upon your perception of what someone can afford? You do not know what they can afford. They are entitled to the information whether they can afford it or not.

Interviewee: I might have $10, but I might not be able to afford to look like that.

Interviewer: Right.

Interviewee: I will get a loan, I will get a mortgage.
Interviewer: It is an excellent point.

Interviewee: Because there are other costs. I mean, it is my econ background. The cost of looking like that may be much, much greater than the money I do not have to pay for something.

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Interviewee: The first time you get to wear a bra, it starts very young. It is the visual perception of a woman. You see that image and it is the curvy woman. It is not the straight up and down and then the hips. To wake up from a surgery and look down and have you completely... it is just a breast, but it is like an arm or it is a part of you. It is not getting your hair cut, because it is going to grow back. It is losing a limb. It is an amputation. It is devastating to them. Then the post reconstructive is like a new world. There is no more hiding, not going to the pool because you cannot put that bathing suit on or making sure that if you had the bathing suit on that your prosthetic is covered or not coming out. They are not directing around it anymore. They are just stressing.

This might sound conceited. I have always been considered attractive. To lose that, not that it would be my face, but is always has been kind of been a package deal. I have always had a cute figure. To lose part of that, again it is losing an arm. It would be drastically changing. That would be a hard step out into the world totally different.

Interviewer: Can you translate that to how you might feel sexually? Because you cannot hide there.

Interviewee: Never taking your clothes off again, not feeling sexual, and we are sexual beings. I have been happily married for almost 25 years. It is part of your entire being. To lose that part of it, and with reconstructive, if it is a kind of hit and miss and if you do not have access to specific things, even the reconstructive sounds like maybe it is not quite as great. Some people maybe think it is. I kind of thought it was. I was picturing it to be more if you were going from nothing to reconstructive, I was thinking more augmentation.

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Interviewee: With the south, I am not supposed to be a sexual being. Good girls do not want to look like that.

Interviewer: I do not know that I would call that southern. I would almost call that our society, I think women as a broad statement have not been given permission to be sexual creatures. I think that we make assumptions. You are a very beautiful woman. It is easy to know that your sexuality would be important to you because you are used to being you. What is interesting is when you interview patients that frankly are frumpy and that it is a natural assumption to think it might not be that high on their list. That is not true. It is really interesting that you just do not know who a person is inside by their outside appearance. It is a topic that is pretty close to most women’s hearts. Even if it appears they are not worried about their weight, or they are not
taking care of something else...you were right when you said breasts are a defining part of our girliness. I do not care what you dress like or how much weight you gained or whatever, your breasts tend to be a pretty strong definer. Some women do not have reconstruction. Some young women do not have reconstruction. It has nothing to do with the age scale. It really has to do with the way a woman interprets herself.

If you imagined yourself going through something in which you were not comfortable with the way your body looked unclothed, do you think that would affect your sexuality?

Interviewee: Absolutely.

Interviewer: So how important do you feel like your physical confidence is to your sexuality?

Interviewee: It is probably 90% of it. For example, for my husband’s 50th birthday in October, they gave him a $50 gift card to Victoria Secret. For him, if mom is not happy, no one is happy. So they gave it to him and it still is in my purse because over the winter I had gained probably eight pounds or so. I said to my husband, “I am not going in to buy any of that stuff until I am happy.” I am certainly not overweight, but it is huge.

Interviewer: So, where do you think you would get information?

Interviewee: They cannot do it on their own. If they do not have the information about what is available to them and if the person giving them the information has not prioritized it as valuable....

Interviewer: Would it even occur to you to say “Can you save my nipples -- If all that you have ever seen is them removed?”

Interviewee: I just kind of assumed it was what had to be. Again, not having gone through it and not really comfortable to say, “Well why did they not save your nipple”, because you are assuming that they would if they could. Going back to the whole outward appearance and it being like an appendage being gone, it is one thing. The principal at the middle school son lost his arm in a horrific car accident. He is fantastic and it was several years ago. It is devastating. You have people looking at you or if you have lost a limb, you get that kind of outward people looking at you and little kids wondering what happened. The difference between that and a more intimate breast removal, it is not strangers looking at you weird, it is with your husband looking at you weird or your kids. I have four kids, not that they would see me nude, but they certainly see me in a nightgown or a bathing suit or something that general people do not see me in.

Interviewer: When you think about taking that into the most precious place you have with your
husband, how do you think that would affect your ability to be the sexy person that you are today? How would that affect your ability?

Interviewee: You would almost be going through the motions because you felt like you have to do this, but you so would not be there in your head. You just would not be there.

Interviewer: When you think about it, when you look at what beauty is to a woman, we are all the same. It is very interesting. So often it is easy to say, “Well, oh that is just vain.” Is it really? Or is it that beauty is just a core element of the psyche of a woman? Does it validates her -- gives her a sense of pride? How would you describe it? How important is your physical appearance to you and how much does being happy with your physical appearance affect your outlook on life?

Interviewee: ... the shower, the hair, the makeup, getting dressed, that is why we have mirrors in the house. It is important.

Interviewer: But how much does it affect you, if you do not feel good about yourself?

Interviewee: It is a bad hair day. Everybody has a bad hair day or has a zit in the middle of your face. It affects everyone regardless of where your level of attractiveness is. If you are a two, you could still have a bad hair day or you are not looking good in your jeans. That is why the makeup business is billions of dollars and clothing is billions of dollars. It is just being human.

Interviewer: How important do you think it is to ensure that women have access to all of the information about breast reconstruction at the point of diagnosis with breast cancer?

Interviewee: I think it is hugely important because like we discussed, it determines decisions they make and also the outcome. If you think going into it, if you have in your head reconstructive is going to look like this, and you have not gone to websites or the information you have been given is not quite what you are going to end up with, and you end up with that, how devastating is that. You have now battled this whole battle and you think you are going to come out in one spot and you come out way short of that spot; that is a whole other dynamic of your psyche. Then you have that battle to face. Your family has gone through this battle and they are wondering why are you not happy; suck it up. And your husband is thinking, “that is fine, let’s move on”, and you are alive, but that is not all. Just being alive is not necessarily quality of life for everybody. Yes it is just a breast, but it is your being.

Interviewer: You want to give that woman everything she needs right up front because what is really hard is when you are delivering a diagnosis to someone and you are not giving them a way out, and it is not just, okay you are going to lose your hair; it grows back. Okay, well that is somewhat comforting even though that is hugely traumatic, but your breasts are not going to grow back and you need the information to know what your best options are. That is why finding the ways to get this message out there to really ensure that women are appropriately armed is so valuable.
Interviewer: I have been working with Dr. Joe down the hall for 30 years. They send them down the hall. Joe may not have done anything different for 30 years. That is how the ball starts. When you think about it, do you have regular mammograms? So who sends you?

Interviewee: My gynecologist.

Interviewer: So, who would get a result if something were found?

Interviewee: The gynecologist.

Interviewer: Correct, and yet, the gynecologist know absolutely nothing about this. That is the big hole really. Every one of us, that is where we start in that continuum; they send you for the mammogram. If you got a bad result, they would call you. That is really a huge gap. They need the education to understand what is available. There is a huge opportunity to really help women, but that is not what anyone thinks of. Gynecologists just do not have a clue. That is going to be an important place for us to increase awareness.

Interviewee: I am in a high risk category because my grandmothers on both sides and my aunt on my father’s side. They consider me technically high risk. I am telling you that I could not beg for a mammogram before the age of 30. Now recently, we do it every year.

Interviewer: Would you consider a prophylactic mastectomy?

Interviewee: To see if I had that gene?

Interviewer: No, prophylactic would mean that they remove your breast tissue and rebuilt you to prevent you from getting breast cancer.

Interviewee: Oh, well certainly, especially since I have the two grandmothers that went through it in their 60s.

Interviewer: What would stop you?

Interviewee: I think being married I would have to talk it over with my husband. I would have to research it to see just so that I have satisfaction because it is such a new thing to me that that is the path that I need to go down.

Interviewer: Have you seen post mastectomy results? Have you seen breast reconstructions?

Interviewee: Only two. I am talking physically. Other than them, I have seen them on the internet. I have seen them on documentaries.
Interviewer: Describe what you see; what is your impression of what you see on the internet or in the documentaries?

Interviewee: Well on the internet, they can go from bad to incredible to worse. It is scary. They are very scary.

Interviewer: The unpredictability of outcome?

Interviewee: Yes. That is where the research comes in and that is where you want to see. When I say I would want to interview five women of this doctor, I want to see what the results are. Are they going to be open with me as I am with them? With my grandmother’s, one grandmother had a full mastectomy and I never saw her at all. She was very private. She carried that shame with her until the day she died.

Interviewer: Do you remember her before and after.

Interviewee: I do.

Interviewer: What personality changes do you think occurred?

Interviewee: I think she became very isolated. I think she felt rejected by my grandfather because she did not feel whole. My other grandmother was completely the opposite. She had an attitude of well you are right, I am not having any more babies, I do not need to nurse any babies and let’s get this done.

Interviewer: Did she have reconstruction?

Interviewee: She did not, but that is how I knew about the prosthesis with the bra. She would put her bra on and sometimes she would look a little lopsided. I would say we need to fix this before we go out. Of course when she got into her 80’s, she did not even put it on. She did not care. So she was that comfortable. Her surgery was, I thought was going to be this grotesque image. She had one perfectly normal breast and then one had been removed. This was in the 1980’s, so I thought it was going to be horrible because my other grandmother never let me see her, so it must just look horrible. I remember when she got sick one time and I had to help bathe her and take care of her in the hospital, it was not that bad. It was not that great, but it was not that bad. I think her attitude was what got her through it all.

Interviewer: Do you think it would have made a difference to her to have had reconstruction?

Interviewee: I do not know. With her, I do not think that was a real priority.

Interviewer: What about your other grandmother?

Interviewee: Yes, I think it would have made a big difference with her life.

Interviewer: How old was your aunt, 40 did you say?

Interviewee: My aunt was around 42 or 43.
Interviewer: Did she have a mastectomy?

Interviewee: She did not. Hers spread so quick and so fast. Hers was a long suffering; I think over seven years. I would have to go back and research that because that snuck up on my father’s side and everybody is gone. I remember her last hope was a chemical wash in the hospital. It made her so deathly ill. She did not live here locally. She was up in New Jersey because her husband’s job had moved up there. I think that we have come such a far way in detecting it. Early detection is the key, but there is more than to just detecting it and getting a cure with breast cancer. For a woman, there is also that reconstruction that finishes the whole picture.

Interviewer: How important do you feel like your physical self is to your overall sense of confidence and wellbeing?

Interviewee: I think on a scale of one to ten, it is probably a nine. I have put on some pounds and I need to get them off; I know that. I broke my ankle about two years ago, so it has taken a while for it to heal. I have had some other health issues and I have not been able to be as mobile and exercise. So, I have put on some pounds. You see a picture of yourself and you think, “Oh my gosh, delete that picture.” I can just imagine if I had a full mastectomy, you cannot get past that reflection in the mirror. It is just a psychological setback for a woman. It is not that I am vain.

Interviewer: Interesting, everyone uses that word. Where did we learn that word and what does it mean?

Interviewee: I think vain means that you are stuck on yourself. I can walk by a million mirrors and never even look in the mirror to see what my hair looks like that day.

Interviewer: Is vanity potentially also being interpreted as caring about how you look?

Interviewee: When you carry yourself, other people look at you. It does make a difference.

Interviewer: The word vanity, it has a negative connotation. So, where do we apply it in this? Is vanity caring about what you look like? Is vanity considering the visual outcome a priority in an illness like breast cancer? Is it vain?

Interviewee: No, I think it’s being confident in who you are and having a positive attitude. As hard as that treatment is, wanting to be whole again and you keep that positive attitude. You are going to beat this with a more positive attitude than you are with a more negative attitude. I think the world puts the label of, “Oh she is so vain.” It is the world’s thinking.

Interviewer: Do you feel like the importance of beauty to a woman is part of how God created a female nature?

Interviewee: Yes, he created us in his own image, both male and female. So, if part of us is missing, then we do not feel whole. Without, do not feel like we are in a complete mix. That does not mean that he loves us any less, but we still want to feel whole.
Interviewer: That absence of what we were created to be.

Interviewee: I think for women too, it separates us from our femininity. We are created different from men. One of the things that make us different from men is that we have breasts. They are not just for beauty. They are for nursing, they are for posture, they are for balance. They are just not two little perky sisters. God created them with a purpose and they are part of us. That is who makes up our identity, our image in God.

Interviewer: How do you think your husband would respond to you going through breast reconstruction surgery?

Interviewee: I think he would be very, very supportive.

Interviewer: Would you fear his reaction at all?

Interviewee: No. We have been married going on 24 years. We have had various scares. We have had some other bumps in the road. We have had cancer. I have had cancer. I had uterine cancer. I think he would support me 100%.

Interviewer: That is interesting. What type of cancer did he have?

Interviewee: He had squamous cell, but it kept recurring. Just two months ago, he had his finger amputated at the second digit. I cannot even tell, but to him, just that one little bit and it is the longest... to him being amputated has impacted his confidence in himself. He thinks that everybody looks at it. He will hold back on trying to hand somebody some money with that hand. Yes, I think he would be very, very supportive because when we were looking at the options of amputation, he had a lot of questions of what is this going to look like. My husband is not a GQ man. He is not worried about things. He will go a couple of days without shaving. In fact, that is why he likes to go deer hunting because he can leave on Friday and he does not have to shave until he comes home, goes to work on Monday. I would not have seen this impacting him. I have watched him and this has impacted him, that little bit of his finger.

It was funny because when they had done the surgery and it was very uncommon that he had this squamous cell under the nail, but when it came back a third time they said, “it has little runners. The next time, it will get in your blood stream, it will get in your lungs and your brain and you are gone.” So option A just came off the table. We were sitting in front of the dermatologist and oncologist and an orthopedic surgeon. The orthopedic surgeon said we only had option B to amputate a portion of it down to where we graft and there are no more cancer cells that will be taken. We left that day and I blurted out, “It is back; we should have amputated last year. Let’s take this off.” When we left, he said, “This is not your finger we are talking about, it is my finger.” I thought that was very funny to me because I thought, “Wow, how would I feel if I had had breast cancer because these are not your breasts we are talking about taking off, they are my breasts...”

Interviewer: What is interesting is that this word is being used repeatedly today in these interviews -- amputation. Very few people really stop and realize that it is an amputation; that is what happens. There is an adjustment curve to that. Now the beauty is that we are able to
rebuild that part of the body. The question is to what degree... there is an awful lot available in advanced techniques, but because women do not even know that it is possible, they are not pushing that bar higher and demanding a better outcome. You have a lot of surgeons that are not well versed in those techniques. When you look at the impact on quality of life that “amputation” can have on a woman’s self-esteem, and then the impact that low self-esteem has on a marriage, you really see that a woman can go through all of that struggle to save her life, but really not wind up saving her life. She may wind up lengthening it, but not really saving it.

Interviewee: She is just faking it until she gets through it.

Interviewer: What does that do to the person that she is?

Interviewee: It has to impact her because -- and then impact the people around her, her immediate family, her extended family, her friends. She is going to start to isolate, I think. I saw my grandmother go through very deep depression times. Unfortunately, I was not as close to her as I was my maternal grandmother who called me into the bathroom and said, “I need you to look at my breast.” On my dad’s side, it was very taboo. We did not talk about it. We did not use that word “breast” in front of mixed company. She ended up committing suicide. She wrote the letter a week before she actually did that. That is what impacted me because my aunt, her daughter, was still alive and I think she had been given the synopsis that she is not going to live much longer than 18 months. She had eight kids. I think for my grandmother, she could not mentally handle that she had probably passed this onto her daughter, not being educated on, yes, maybe you did pass that on to her, but this is what we know now. I think as a whole, the medical society has done a really botched job, in my opinion, and it may be because we are women. For so long, women were held down. They were not equal to men. Had it been prostate cancer, I think there would have been a lot more. It took women starting to do 5K runs to bring it to the world’s view that, “Hey, this can be curable if we detect it early.”

Interviewer: How do you think it would affect your sexuality with your husband if you were unhappy with a part of your body?

Interviewee: It would have great impact because we would go back to when I first met him... I went through a horrible divorce. It took us six weeks into our marriage before I would even let him have the lights on. He remembers that. He says, “When we first got married, you would not even let me turn the lights on; now you run around with the lights on all the time.” So, I think if I could not have a reconstruction, it would throw me back into, “Okay, let me go back here, I will get under the covers, I will turn the lights out and you will come back in five minutes.” I am not going to go from being a very confident sexual woman with my husband, or my significant other to, “Oh my God, I wonder what he thinks right now.”

Interviewer: What if you had a breast reconstruction that did not please you? Let’s say you had breast reconstruction, but you felt dented or scarred or were not satisfied. Do you think it would affect you the same way?

Interviewee: I think so, yes. It would be like the devil planning. Would I have been better off just not having it done at all?
Interviewee: I think it is part of my responsibility as the patient, but I think it is also part of the doctor’s responsibility. If you are in a small town in Alabama or a small town in Wyoming, and all you have is this one little network of doctors that have not expanded out, we are not as advanced at New York or Los Angeles or even Huston or Vanderbilt, but we still have a good network of doctor. I just hate to think of these poor women that sit in these little towns in the middle of nowhere and their surgeons just look at them and says, “well you have cancer and we are going to take them off and then we will do chemo, radiation and hopefully that works” not “let’s look at this and maybe let’s get you down to Nashville where we are successful or up to New York.” I just think at the end of the day, it takes a tribe to raise a family. It takes a team of doctors to come together. We had a pathologist. We had an oncologist. We had a dermatologist who we had gotten a third opinion from that finally said, “Whoa.” We had an orthopedic surgeon. They all came together as a team and they heard our voice.

Interviewer: That is a huge point. In breast cancer you do not often have a multidisciplinary approach. In fact, really one of the things that has been identified in this over and over and over and over is that gynecologists are the ones that start the chain because they are the ones that send us for mammograms. They are the ones that tell us if there is something bad on the mammogram.

Interviewee: That is their expertise. They send you on down when they should really... A gynecologist, for some women, it is their only primary care physician.

Interviewer: That is right.

Interviewee: They do not have another. My mother only had a gynecologist. When I tell her, go to the doctor you have a cold, she says, “Well all I have is my OB/GYN.” They are the starting point, but they do not need to pass that ball. There is no I in the word team. They need to be part of that team because at some point, that patient is going to come back to them and they are going to be their only doctor.

Interviewer: That gynecologist is the first influence. They really need to be much better educated about options. At this point, I have talked to many. They do not know anything about breast reconstruction. They are in a key position to influence, but they do not have any information.

Interviewee: That is part of that hope that “you are going to get me back to where -- or at least as close to back to where -- I was before this all started.” It is a journey. It is not just like going in and having your appendix out.

Interviewer: Talk a little bit about your perception of your breasts as a part of your sexuality, or how you feel that would relate to your self-esteem.
Interviewee: I don’t know that I would... I’ve never had any type of surgery, so to think that something might be removed would probably make me feel very uncomfortable. And I’m the type of person I want to put things back the way they were before the problem occurred. So I think I would want to have the... have my breasts looking the way they did before I had them removed.

When my sister went through it, she was very scared, and she did lots of research on the internet, which depressed her even more. When she thought she had found a doctor that was going to be able to meet her needs, that doctor did not really follow through. When she called and asked some in-depth questions on what she was going to look like, they couldn’t give her that. They told her it would be better just to save her life and don’t be picky. And that is not what I would want anyone to go through, myself or anyone else. And if it wasn’t for her determination to find the doctor that was going to give her her life back, I don’t know that she would have went through with it.

Interviewer: And what would the risk of that have been?

Interviewee: Well, she went through the procedure to eliminate her risk or decrease it highly of cancer due to the BRCA gene. She would have been miserable, because she wouldn’t have had the reconstruction done, because she didn’t want to look deformed even more. I think that’s a pretty high risk, because you don’t live your life if you’re not happy.

Interviewer: Do you think women, in particularly, are more vulnerable to having a less than ideal physical outcome affect their self-esteem?

Interviewee: Most definitely. It starts at a very young age when you’re in middle school now, to where you’re condemned for any little thing, and you’ve got the media that tells you you’re supposed to look a certain way. And too, I don’t know the answer to how you get past all of that, to be able to have a strong enough self-esteem that it is not influenced by the world in general, what the world’s expectation of what a woman is supposed to look like, what men tell you is their expectation. So it affects a woman a lot on how she looks and how people perceive her.

Interviewer: How important do you think beauty is to a woman’s overall ability to heal, to move forward after a major life event?

Interviewee: I think that women in general, if they’re not feeling good about themselves, get into kind of a depression or a “not ready to move forward” type of state, and it could inhibit healing tremendously.

Interviewer: I think you did have a conversation with a gynecologist, and if I remember correctly, you talked about nipple-sparing technique.

Interviewee: Yes, and I don’t remember the conversation very well. I remember that I had caught her at a bad time, after she had just worked the weekend, and she called and apologized later, and I don’t know that she... she didn’t show an interest in it, but I can’t really remember the conversation. She didn’t consider that safe, and she felt it didn’t eliminate the risk for future cancer.
Interviewer: And then when you asked more questions that would back up that assumption on her part that was when she called back and apologized and felt that she didn’t have enough information?

Interviewee: Didn’t have enough information, and then I had just caught her at a bad moment, she said. But it’s never been anything she’s ever brought back up, or I’ve brought back up to discuss.

Interviewer: So if you were diagnosed, how do you think that event would linger in your mind, and where do you think you would start?

Interviewee: I don’t think I would have a lot of trust for my doctor’s advice. I think I would seek advice elsewhere.

Interviewer: Where would you seek it?

Interviewee: I guess I’d be back to the internet.

Interviewer: In the circular argument, when you were on the internet, what did you find, prior to knowing anything about Dr. Maxwell?

Interviewee: Nothing that would make me want to have surgery. It would kind of make me want to not go through anything, in a way.

Interviewer: That’s an interesting statement, because we both know there are women that choose nothing, and we’ve both seen them die, and so, if you look at what you just said, you said, well, if I went to my doctor, then I don’t really have any faith they would have any real information, so I probably wouldn’t go there, so then I’d go to the internet, but gee, I’ve already been there...

Interviewee: And there’s no hope there.

Interviewer: So it creates a very frightening circle, and then if you combine that with the pressure of time...

Interviewee: Exactly, because every doctor, once you’re diagnosed, is ready to move forward that week it seems like to resolve the issue.

Interviewer: And if you don’t have the information, you don’t even begin to know where to start.

Interviewee: And your spouse doesn’t, and he’s all upset, and he’s just wanting to make sure you’re gonna live. It would be very scary.

Interviewer: How important do you believe your satisfaction with your physical self would be to your overall healing, scale of one to ten?
Interviewee: I give it a nine, only because I feel I’m a pretty optimistic person, and I try not to be hard on myself, and I think that my husband is a very supportive husband to where he does not point out my flaws but is always positive and encouraging.

Interviewer: So, but having said all that, you would still give it a nine?

Interviewee: Yes, ten being top, I’m giving myself a point for being optimistic.

Interviewer: When you feel confident about your physical self, do you think that gives you a sense of victory over obstacles or challenges in life?

Interviewee: All the time.

Interviewer: And do you think that the same thing would apply if you were facing a disease?

Interviewee: Oh yes. I believe that your mind and your emotional state play a critical role in how you handle it and how you get through it.

Interviewer: How valuable is your confidence in your physical self to your ability to move forward in and after a tremendous issue? For example, if you were diagnosed with cancer, how valuable do you feel your confidence in your physical self would be to your ability to put it behind you?

Interviewee: I think I would be able to put it behind me and move forward. I feel that once I get through something, no matter what type of struggles in my life, I don't dwell on the past. I move forward.

Interviewer: But the question is really, how important do you think being satisfied with your physical self would be to your ability to move forward?

Interviewee: I think it would be highly important. I would give it a ten.

Interviewer: When you feel confident about your physical self, does it enhance your relationship with your partner?

Interviewee: Yes.

Interviewer: Sexuality?

Interviewee: No one wants to be making love when they don’t feel good about themselves.

Interviewer: So on a scale of one to ten?

Interviewee: That rates high.

Interviewer: So if you felt great about your physical self, it would have a huge impact on your sexuality?
Interviewee: Yes.

Interviewer: Are you comfortable with complete nudity?

Interviewee: Yes.

Interviewer: Would you perceive that you would be just as comfortable after breast reconstruction, given the kinds of results that you’ve seen firsthand now with Dr. Maxwell’s work?

Interviewee: Good thing you added that last part. I think so. I don’t have a problem walking around naked now, and I don’t see that I would, being happy with the results that I’ve seen in you.

Interviewer: And what do you think the average person’s perception of the results you’ve seen with Dr. Maxwell’s work would be? Do you think they would consider them... on a scale of one to ten?

Interviewee: I think they would probably, if they had taken time to look at the other options out there, they would give it a 12, because they wouldn’t have even had expectations that high.

Interviewer: From a patient’s side, I can’t say enough about the importance of those qualities, because when you’re on the patient side, you’re really trying hard to execute your vision. You’re on to something huge, and everything’s been taken away from you, and you’re trying to maximize your potential in the end, not necessarily migrate from... at first, what you want is just somebody to tell you you’re gonna be exactly how you used to be, and then you go through so many changes, that you lose sight of the past, which I think is actually rather a healthy thing. And then you begin to take stock of who can I become in this? What could I be that’s different than I’ve been before? How could I come through this? And that’s where I find that you reach a lot of stumbling blocks, because you have to have the right knowledge and the right practitioners that come together to execute that vision. I think most people who are visually oriented as a patient, well, it can become very mind-consuming....and you’re just working so hard to execute that you can lose sight of the fact that you’re still a whole person.... and that some little thing you’re working on over here, on your own little piece of art, is really unimportant to those that love you... and though they’re gonna support you; you haven’t lost value to them because of it. And that is a tough balance, and I think one of the things I’ve seen in all of this is a tremendous compassion from my friends for the doors that get slammed in your face when you’re dealing with a fractionalized medical system, and you’re looking for answers that need to come together.

So having those friends and family members give you unconditional love and support in whatever piece is gonna be the completion of your journey, I think is huge. I also see trust is huge. I think from the patient’s perspective, when you’re going through something like what I experienced, you can lose your perception of yourself. You can go through moments where you no longer know what you used to look like or how some things supposed to all come together for a whole look. You can lose your perspective, and you have to have those family members you can trust and that can look with you and help...
I think having that level of trust is important, and I think you gave that level of trust over and over and over again. And I think... I never thought about it, I never thought about how you might have felt, like “how do I play this role I’ve been thrust into?” And I think it’s probably one of the most important things you’ve said here is that two people get thrust into that role. Three people... we all get thrust into that role. My children were thrust into that role. Everyone close to me was thrust into that role, but from the patient’s perspective, you don’t really realize that. And grace is that nobody reminds you of that. Nobody’s telling you that they’re catching up too, and they don’t know how to do this either, and that’s really humbling to realize their words, that we all were in the fire. Because when you’re the patient...you just burn...

Interviewee: The focus needs to be on you, because you are the one who needs to come through feeling good.

Interviewer: And as a patient, you can’t even really define “good” that well, and I think that something you said was huge, when you said, “a person doesn’t even know what they need”, and I think that that’s a huge growth process, and having those people that love you help you figure out what you need is critical. I don’t think you can do it alone. I think that is something I’ve learned through this, that this is huge, that there’s nothing I’ve accomplished on my own. We’ve done it together. It’s been this family unit that surrounded me, my kids, you, my other close friends that just really surrounded me and were willing to take on the journey. And I think the other important thing I learned as a patient is that not everybody will go on your journey with you.

Interviewee: That’s what I was thinking too, because I can remember you talking about different friends that were not supportive.

Interviewer: And some that caused great pain.

Interviewee: They might have had somebody in their family who had cancer, and they didn’t want to go through it again with someone else.

Interviewer: I think to that point too, and that’s a great example, is that when your support system has had a prior negative experience, without meaning to, they can put that on you.

Interviewee: Well, you bring up memories.

Interviewer: ...it also puts a weight on the patient of ideas that maybe they’re not gonna have a positive experience either. And that is a weight that is very difficult to bear, because you so need those around you to believe that you’re gonna come through this, and to keep seeking faith over you, and to remind you that God has His hand on your life and is bringing you through. And I think that of all things that is the biggest element. What other things did you learn going through this?

Interviewee: The acceptance of the anger the tears and denial, a little bit in the beginning. That the person is so overwhelmed and if they’re given a diagnosis by a doctor that seems overwhelming, and the doctor speaks words that are not very promising, it’s taken to heart whether it’s true or not.
Interviewer: You’re reminding me, and I’m remembering being in that hospital bed, and in a way, maybe people have one of two reactions, and maybe not a lot in the middle. Maybe they either fall apart, or they fight back. I mean, maybe that initial reaction is a real important one.

Interviewee: And how they’re gonna deal with the journey.

Interviewer: Whether they’re gonna accept it or not. Because there was a lot of negative news, wasn’t there?

Interviewee: Yes, there was, and unexpected negative news, which makes it even harder.

Interviewer: If you navigate it together, I think, I look back over our journey, and there’s nothing we have not talked about. We’ve talked about anything and everything up one side and down the other, and I think, I mean, I’ve been close to you most of my life, but yet I’m closer to you in a different way. It’s not even definable anymore, but you can easily say, “oh yeah, I enjoy this person”, or “I like this”, but it’s when you are in a battle for life together, something changes that beyond words. There is a new level of understanding and having gone through this single, I can imagine that must be a positive element of what happens as a couple, that they must come through much different because it’s on a whole different plane. But I know this in myself; I’ve always been a very loyal person, but even people on the periphery now that were part of that journey with me helped me. I don’t think they know how committed I am; they are like threads woven in the fabric of my life. Some people are around the edges of the tapestry, but you, my kids, others that have been really close to me; those are like front and center. But anybody that gave you a hand, that was kind to you and lifted you up, where others would push you to the ground, they’re in the border of the tapestry. They’re in this forever painting in your mind. Nothing’s ever gonna take that away. I don’t know if people fully realize the role they play -- just how they are literally part of saving someone’s life.

Interviewee: I don’t know if some do either. I know that they probably feel that they’re amazed at your outcome. I think they probably feel that they’re not too sure they could have gone through it, because I think everybody tends to think that when they see somebody come through it so well, “Would I have had the stamina to search out all these doctors, to come out on the other end looking and feeling so good?” And then you’re gonna have those that are the naysayers from the very beginning, and they still are. The ones that thought you were beautiful before and are upset that you still are beautiful. I think you’ve had all of them come into your life in the last year.

Interviewer: What’s strange is that there must be a certain survival element. I don’t remember much, like when you say, I’m sure there are people that think, “how did you come through this”, or “could I have done it?” I don’t remember it being hard. There are seconds where, when you reminded me a moment ago of being angry at the diagnosis, I don’t remember that until you say it, and then it’s like, darn it, I do, I was mad, and you got mad at me too... (laughter) because I wasn’t behaving at that moment (mutual laughter)... but, I don’t ever remember anything like it being particularly hard. I have these images in my mind that I kind of remember of how hard it was, the hats, or if I talk about it, how hard it was to lose my hair, or if I see a picture, like in the documentary, that photographic journey where that stunned look is on my face, and I don’t have a hat on, and I have on the same dress I had on when months earlier I had all my hair, and I felt
great... I remember that, but there's very much an element of putting it away, and in my mind it's like rock climbing, like you're trying to get to the next ledge and the next ledge. You're never looking behind you to see how far you've come; you're always trying to get to the top.

Interviewee: And that I think is more of a personality trait; you either have it or you don't, because there are always people who live in the past and bring up the past, because they're unhappy. And that's why they're unhappy, and they're gonna let everybody know that's what caused their unhappiness, and they never move forward. But those that move forward are the ones that have the determination, that have the confidence that they can do it and don't look back. Because I think you have two different styles of people, and you can recognize them pretty quickly, those that are most vulnerable and those that are positive and moving forward and not looking back.

Interviewer: I think another element there though is possibly what you can fix and what you can't, because...

Interviewee: And if I can't, don't you have to come to an acceptance?

Interviewer: I think, at least in my journey, I think those things I felt I still had the potential to fix took me forever and a day to get to some level of acceptance that they weren't going to be fixed. But those things, like there was nothing... I had already been diagnosed; I was going to chemo, and nothing was getting me out of it. I already had the hysterectomy and nothing was gonna change it; I had a BRCA positive gene, so nothing's gonna change that. Looking back on those elements was useless. Looking forward was, okay, what's the leftover damage, and how do I solve it? That becomes an exercise of combining as much knowledge as possible and getting to that next step. But in situations where you think if only you look back hard enough, and you could come up with a reason why something happened, and therefore you could change the outcome, I think those are things that people can get stuck on. But events like what we're talking about, it isn't gonna matter why. You can't figure out why; it isn't gonna matter why; it's done. It's almost easier, I think, to move on from an event like that, 'cause you can't, there is no chance you're gonna fix it. Nothing's putting my ovaries back in place, so you're kind of like, we have to move forward. So there are patients, I do talk to a number of patients that struggle with just sort of always living in the cancer mode. It's always on their minds. They're always dwelling on it. They're always thinking about it.

Interviewee: Are they early or later, like so many years? I'm thinking about lots of ones that are one, two, three years out, or are they still ten years out thinking about it?

Interviewer: The higher percentages in the early years, though there are people that it defines... It becomes the greatest thing that happened to them, even though it was negative, and it becomes this defining thing. And I think the other set of people, and I think these people do best—they feel it's a bump in the road. It's like, okay, been there, done that, got the tee-shirt, burned it, over it. It seems that those people move forward more rapidly and that they go on to do much bigger things. It's just one of their life experiences, not their major life experience. Is there anything else as you've thought through all this that you've learned that is important to you?

Interviewee: That you're the first person I'd call if I were to ever get... that if I were to ever have...
cancer, you’re the first person I call.

Interviewer: I’d be right there, too.

Is there anything that you would say in closing that would be important to referring physicians to know about how a woman’s sense of beauty affects her confidence or her overall wellbeing? Part of the importance of this message is that physicians, who handle women at the point of diagnosis and have such a tremendous amount of influence, realize how important it is that she is actually preserved in the process and that she feels good about who she is as she comes through it. What would you say to physicians that would help them to understand what it means for a woman to feel really good about who she is and what it does to her relationship with her spouse?

Interviewee: I would ask them, if they bought Playboy, did they buy the ones with breast-less women or the ones with large boobs.

Interviewer: Your point being that it’s important to you as men, and we know it?

Interviewee: Yes.

Interviewer: I find it really interesting, because one of the things that seem to go on is that men are extremely visual, sexual creatures, until they’re problem-solving, they become very practical. So when they have a woman sitting in front of them, and they have gone into the mode of “we need to save a life”, they very often become very practical, and so they say, “Well, don’t worry about that; we’re here to save your life.” But what’s interesting is that women know that men are very visual, so they know that their mate isn’t necessarily going to be thinking just that way, and closing that gap for physicians is really important.

What would you say to a woman who was facing diagnosis and needed to feel the support and the permission to seek the best visual outcome? What kind of things would you say to encourage her?

Interviewee: I would first of all tell her from my own experience that “no” is not an option, and “no” is just a word that gets you to the next question. And then that question and the next question, and to keep researching things ’til you find the answer that you’re seeking and get the answer that you’re looking for.

Interviewer: Is there anything else you would say in closing?

Interviewee: Women need to protect themselves, because no one else will. They need to stand up for themselves, because you’re the only one that can make sure that you get the response to the questions yourself by asking them.

Interviewer: What is interesting is you are very consistent in that most women think that they would come through it like a breast augmentation. That is common.
Interviewee: So, what you are saying is reconstruction and breast augmentation are worlds apart?

Interviewer: What I am saying is in many, many situations, they are. It takes a highly skilled surgeon and there are advanced techniques that really provide something amazing today. Very few surgeons actually perform the surgeries that way. Referring physicians do not often give women information that would allow them the best opportunity to meet the expectation you have in mind. So, this work is really about raising that bar. Because for women, if you can imagine a woman at the point of diagnosis, it is a rapid decision making process. She often will go into that thinking that, “well, okay it would be like this”, it goes one of two ways. If she has no exposure whatsoever, she thinks it is going to be like a breast augmentation, and then quickly her hopes are dashed when she gets on the internet and she sees what the outcome generally looks like, or it could go the other direction -- women who have already seen other women who have been through it, and they are frightened by it. Because of that fear, they will often make poor healthcare decisions, so they will avoid treatment; they will not do what they need to do.

It is possible with the right combination of the breast surgeon, who is the one that removes the tissue, and the plastic surgeon, to meet an expectation like you were describing. When that breast surgeon is not functioning from that level of skill, he leaves the plastic surgeon with little to work with. When a plastic surgeon is not highly adept at reconstruction, the results are far different than the visual that you have in mind. So the way to change that is for women to know what is possible and for them to set that expectation and seek those who know how to fulfill it... and for referring physicians to really be in a position to provide the right kind of information to women and not just send her down the hall to Dr. Bob who has been doing the same thing for 30 years and has not improved his technique. That is really what a lot of this is about.

Your face changed when I took that away from you. You had a thought, you had an idea that this would be okay, I would look even better. That is such a precious place to come from. If you think about what that can mean to a woman and her sense of healing, how do you think it would affect you if you were in such a situation and then learned that your outcome would be something that made you uncomfortable?

Interviewee: You are coming from an area where accept what somebody tells just because they are supposed to be the expert. We all do that a lot. We listen to somebody who is supposed to be in charge who is supposed to know what they are doing. That is why we go to them. You take that and you are supposed to be able to trust that. (bursting into tears)

Interviewer: What affected you so deeply there?

Interviewee: My husband is a really strong person. He has his opinions, but he also says a lot that, “just because somebody SAYS they are an expert does not mean that they ARE an expert. I know how to fly airplanes. I do not ask a doctor to do my job. I ask them to do their job.” He does a lot of research and stuff on the internet for different things. He may be uncomfortable with something for a while and he may procrastinate on it because he does not know how to do it, but would bookworm on it all. So, my thought was what he would do. He would not ever settle for somebody telling me that that is as good as I can get. He would do what you did and he would go and find the best he could. He would never settle for mediocre. That hit my heart because he loves me that much and because there are so many people out there that just take...
for granted the words of somebody who is supposed to know better.

Interviewer: What hurts me is when a woman finds out that it could have been different. Only now there has been a lot of destruction and it can never really be what was possible. Looking at your face and how that hit you, you really experienced it. It just kind of went all through you as you thought about what that would be like for a woman. The first thing you said is, “he would research and go on the internet”, but what happens when you do and there is not a whole lot of information out there?

Interviewee: We are already feeling guilty for asking.

Interviewer: One of the things you just defined was that your husband would be a very strong player and that you would be a team.

Interviewee: We are always relying on somebody else to know what is best. I think that is one of the reasons why it hit me so hard was because there are people, including myself, who would have at one time said, “Well, I guess that is okay if that is all I can expect, if that is what is going to happen; if this is how you do it and this is how it is done.” If that is what you expect and you settle because they are supposed to be the expert, then you would not go looking for something else, unless you come along somebody like you, or maybe not even quite as knowledgeable as you, saying, “well did you ask him this that and the other?” and well, no we did not. Then maybe you would find out that there are other things and maybe you might ask a question where it would not be so easy for you to get stonewalled and accept what they gave you.

Interviewer: Would it be difficult for you to argue back for the result that you really want?

Interviewee: I do not think so, no. I do not think so because I have the backup, but listening to you just in that moment of realization where you are like reconstruction and augmentation are not the same and I expected them to be the same... you said that you had wanted to be whole. I guess you could say that they would do a good job and they would not leave you scarred and basically disfigured, which is so important to a woman anywhere on her body. I do like being fit even though I am not fit right now. A woman’s features are so important to her.

Interviewer: How do you think it would affect your sexuality with your mate?

Interviewee: It would probably take a lot of coaxing on his part because she would always be self-conscious. I think you would be very self-conscious about how you looked. You would want to hide or wear something over it.

Interviewer: You did such a beautiful job of capturing the essence of failed trust, just how that wave went over you in the words that you were using that you were counting on someone. You are counting on somebody to tell you what you need to know and that you can trust what they said. That is just a huge component that there is an ethical responsibility on the part of referring physicians to know what is possible and to share that information with a patient who is so fragile at the point of diagnosis and time is not on her side. A prophylactic mastectomy was different because I had the time to do the research, but at that point of diagnosis she is rapidly being put through very quick decisions without enough information. Making sure that that is available is a tremendous issue.
Interviewee: You kind of go to the vanity issue where you want to look pretty.

Interviewer: What is vanity? Is that a word we have been taught?

Interviewee: I am sure it is. What you think about your looks and how you are. I think there is probably, with some people, there is some guilt for thinking about how you look, that that is so important because they all say it is on the inside that counts.

Interviewer: But is it really?

Interviewee: It is; it matters how you feel about yourself and your inner beauty carries out to how you look and what your vibe is that you give off. That adds to your beauty. You could be just kind of, at a glance, a humdrum woman, but when someone gets to know you, they see that inner beauty and you just become beautiful to the eyes because of your heart. I think society puts a lot of pressure on us to look good with all the models, makeup ads and hair ads. I can see how someone goes and tells you that you are vain because you want something done and that you feel guilty about it, because deep down you are not sure that you should do it because is it vain or it is just trying to improve the looks that God gave you kind of thing. I think that it is very biblical to be able to go in that direction for making what you were given better.

Interviewer: You think it is or is not?

Interviewee: I think that it is a fine line between being a want versus a need, but I think going through that kind of situation, you would need it. It would be a need for your soul almost to help you heal and just to make yourself feel like you.

Interviewer: You think you are amazing. I think watching you have the guts to actually try it on, you are so empathetic and you are pulling this right through your psyche, right through who you are as a woman. You are like taking in this experience and it is affecting you because you are empathetically reacting to it. It is so beautiful to watch that because you are not in the situation, and yet it is so core to your femininity and so core to the woman that you are that you are grasping it and getting it as if it were really happening to you. That is what we have to translate out there woman to woman... you are not even in that experience, but you can reach out and touch it so beautifully because it is core to the female nature, because it is what we are. It is not vanity, and that is why I asked you a little bit about that word... as if this essence of us is somehow not a good thing and that if somebody is going to save your life, how could you ask for this superficial thing when it is actually a core thing? I think that is what is so beautiful about what happened in some of the places that you have explored here, is that you are identifying and recognizing that this is just the basis of the female psyche. This is not a bad or good thing. It is a thing; it just is. When you look at the responsibility physicians have to make sure that that is not taken from a woman, that is not a light thing. It is not a deflective, “oh we saved your life, what else do you want.” The essence of femininity sits within that experience.

They tell us, “We need to fix this.” They are myopic and linear. “We need to fix this and we need to save your life. That stuff does not matter”, but I think they forget that we already understand it does matter. Interviewing men has given me an added perspective. They express that they are very afraid of the visual outcome because they are visual creatures... and they are...
scared to death for anyone to ever know that they are afraid because they love their wife and they do not want her to feel insignificant.

You said something really gorgeous when you said you would look to your husband and he would step up to the plate as your protector and that he would work hard for what he would know would be important to you. A lot of men are in a situation where what they are hearing is, “I do not care what it takes, she needs to have that surgery, we have to save her life”, and they go into the problem solving mode. The rest of that data concerning the best techniques for an optimal visual outcome may not be shared, if the doctor is not focused in on that part... then a lot of men realize later that their wife is alive, but she is broken in spirit.

I think that is the point in which we do not need permission. We do not need permission to need that feeling of wholeness. It is something that we need and it affects our wellbeing. In closing, what would you most want to say to physicians that are in the position to give women information that is vital to their decision making? What would you want to say to them about what beauty means or what the importance of this would mean to a woman in terms of the way she would live the rest of her life?

Interviewee: I do not care what kind of position you are in, you should never degrade a woman because she wants something to improve herself, her body, even if it is just looks. The other is that if you have been doing it for too long and you are not willing to be open and listen to what a woman wants for her treatment or for her whatever, then you should not be doing what you are doing anymore. The other one is to maybe in your practice, especially if you are dealing with this horrible disease of cancer, open up your heart to think about what you appreciate about women when you see them and want to give her that when she is done healing the physical part and give her her spirit and her love and her beauty and let her keep that whole. That is where it should come from. Men are the admirers of women. They are the reason why we want to look great. That is what the surgeons should be doing is to as much as possible make them whole and make them look like what they would like to look at.

Interviewer: When we talk about whether or not women feel they are given permission for beauty, how do you feel about that from a cultural perspective?

Interviewee: That is such a good question. I went to an all-girl school. There was huge talk of feminism and it was like, the girls who were the most beautiful and most put together and came to class looking the most refined, typically people did not respect us as feminists. Because, you are trying to look so good, why are you wearing those heels to class and this is an all-girl school, but I am kind of part of, I guess you could call it the second wave of feminism -- which is you embrace your femininity and you dress up. I like it. I think you are responsible for your beauty and of course, I romp around in yoga pants all the time, but I also really like getting dressed up. I have had that about myself since I was little. My first bikini was when I was like six. I do not want to say being beautiful to me means like showing off your body, but it definitely means working it. That is huge. Femininity and embracing your curves and your body is a personal decision, but I am proud. I feel like everyone should be proud. I think if you want to get your hair highlighted, get it highlighted. I think that there is nothing wrong with that. There is nothing wrong with spray tan. I have been known to do it a couple of times. I think it is fun and I
think it is an important part of being a woman. I do not know; we are very blessed. Men are so lucky. I think you have to rock it; I do. I think that in a post cancer treatment kind of situation or setting... I thought about this last night a lot. I actually talked to my husband about it. I said, “How would you feel, if I had a mastectomy or double mastectomy, what would you think? Would you want me to get anything redone?” He said he really did not know how to answer it. I said “You are not going to offend me if you say you are with me for any reason other than my amazing mind.” He laughed and he said, “Well, you obviously have to make the smartest, safest decision.” He said, “I love your body and I would want you to feel proud and happy.” That is more important to him because he knows that he has a better wife when I am proud and happy. When I strut around and I feel good in my heels, I am a little more fun than I might figure. I really am. So, he knows it means more to me than maybe even I let on to. He says, “I would want you to be proud and happy because that is when I love you most and that is how I love you.” It is funny. I think the right answer is I would want what you would want and nothing more, nothing less. I think he knows what I want is to feel completely feminine.

Interviewer:  When you say to feel completely feminine, what would it take for you to feel completely feminine?

Interviewee: I look down at my chest and I thought if I did not have -- I do not have big ones, but if I did not have them, I completely think about my outfits I choose. What would it be like? Now that I am pregnant, I am choosing outfits based on the expanding belly; I have never had that before. I am also choosing them on these expanding boobs; I have never had those before. So, I look down and I was like, you know what, I do not have much, but I do not have nothing. So, to go to completely nothing, I mean it would be really hard. I even said to him I would get really skinny, I would go Kelly Rippa and just get like completely rai thin. He said, “No; what is wrong with you!!!” (laughter) What I am trying to get at is I would have to find a new femininity. If I did not have breasts, I would have to figure out what that means for me. If that means I am going to be -- but look at me trying to change my shape entirely just to fit a feminine mold if I do not have the curves.

Interviewer:  What is interesting about what you are identifying is a gravitation factor towards something you could be proud of. I understand because when I went through chemo and I lost my hair, my style changed radically because I wore hats and there was a certain hat that looked good on me, kinda of a pageboy look. I chose clothing and jewelry to suit a look. It was not me, that look was not me.

Interviewer:  That is exactly it.

Interviewee:  That is the way I could best present myself given what I had to work with. So, even jewelry was larger, or whatever was large, the hat. What you are saying is that you would then adjust your body type... your way of dressing to try to still seek that sense of confidence.... So, let’s think about breast reconstruction for a moment. In your mind, as someone who has never probably delved too much into that, what is your expectation of what you think breast reconstruction would look like?

Interviewer:  That is interesting. Physically on the outside, typically I think of a tennis ball. You would think it would only be like a tennis ball and great cleavage. You recognize it from a mile away.
Interviewer: Kind of the headlight look that you would have with breast augmentation in the past?

Interviewee: Yes, exactly. Just like the disks with the model type of look, but I do not think that is the case anymore. I think they have come a long way that is not just like pucks. It more of a softer look, but I am still stuck in that kind of, tennis ball look, which is a very firm like and perky.

Interviewer: So, your impression then is that breast reconstruction would look like breast augmentation?

Interviewee: Yes, exactly.

Interviewer: I think it is because from my impression, if you look at the Susan Komen Foundation, its mission is very specific, to cure breast cancer. It has remained extremely focused on that mission. What it has not done is address the women that have faced breast cancer and what the solutions are for them. I want to go back to something you talked about in an all-girl school. You talked about the first wave of femininity and the second. To me, I feel almost a lot of what happens in breast cancer is kind of following the track of the first wave of femininity.

Interviewee: Oh, I think so too.

Interviewer: Talk about your impression of that.

Interviewee: Well, I think the first wave it was kind of forward. There was the 1920s wave and then the 1960s wave and then there was the 1990s wave, so one, two, three. The first wave was kind of a little bit irreverent, a little more fun, a little more wild, but I think that that does not really relate here. But what I think it was, was kind of no frills. The first wave was kind of no frills. I think just like you are talking about the first attitude towards breast cancer. It became more popular in the 1990s or the 1980s, I do not know when, but it was kind of, okay get it out and get on. I am still a woman and I do not need my breasts to define me. I think that would be huge for that parallel. The second one was the 1960s, the sexual revolution. It was kind of like really embrace your femininity and your curves. It is all about how much more you have, which is terrible, but I mean if you are talking about feminism, it is pretty one sided. Your body is huge in that revolution and you are proud of your body. People did not wear clothes because they were proud of their bodies in the second wave. You definitely find people that are much more aware in more of like kind of a holistic feminine way. Then, the third is a different wave entirely. It was called raunchy revolution. What it is, is you are using your body for sex a little bit more and you cannot deny that breasts are involved in sex. That is a huge part of most peoples’ lives. I think that would be relevant there. I would say rocking it would be a little more of that third revolution, which is really saying, “I am sexy, I am a woman and you should love me.” I think that knowing these options, women are going to feel a lot less like just a statistic and more like a survivor because they are saying, “Look at me, I have been through this and I have bounced out of it. Now I am back into my femininity versus I am a survivor. That is why I look like this.”

One is kind of wearing what you have been through, which is kind of really hard and people are
going to look and people are going to ask questions. It is going to happen, like at the beach. The beach of all places, it is going to be obvious. Then you have the opportunity to say, “I am moving on from this and this is not going to define me.” I think reconstruction kind of brings kind of a new, I do not know, like the next level and back to where I was. I think mentally it separates what you have been through and where you are going. That is what I thought. I thought I would probably get reconstruction if the question was asked to me because I do think that all of your mind does that. I think I would want to say that was horrible, that was traumatic, but I have a long life and if I am going to live it in the shadow of what I have been through, it is not going to be all of that wonderful as it could be versus saying, “I am going to move on, I am going to look my best and it is not going to be a question that comes up once a week.” Even now, I think that is how I feel about it.

Yes, and separation, not that I would ever want to lose that pride of being a survivor. That is a huge amount of pride. I go to the doctor and I have a clean report, and I am like yes! I am proud. So I would be very, very, very proud of being a survivor, but I think that there is a time and a place for that. I think I would be the kind of person who says, “Well that is behind me and I want to really feel confident and beautiful.” I do not want it to be a conversation that always comes off as a fight. If I am sitting there and I feel uncomfortable about it because we know we are women. If I had a zit on my face right now, the whole time I would be thinking she is looking right at it. Women just do that. I do that. I cannot imagine what I would do if I was completely without my breasts.

Interviewer: What is very interesting is that as you try to get your mind around this, you think of it one of two ways, with and without. What is interesting is that there are a large percentage of women that have had reconstruction with a far less appealing visual outcome, because I think most women enter the thought process similarly to yours unless they see poor reconstruction. They assume just that of course, I went through this and it would look like a breast augmentation and here you go.

Interviewee: Yes.

Interviewer: So, if you thought about that, how much do you think it would affect your self-esteem as a woman if you felt like your breasts did not look good?

Interviewee: Oh, that is huge. The only thing I could compare it to is early on in my pregnancy, one boob was way bigger than the other one, like way bigger. It was ridiculous. You could see it in the shirt. I was super embarrassed about it. I did not like it. I was like, “Oh my gosh.” My husband would look at me, and I was like, “No!” So clearly, history is the best predictor, I think I would be pretty disappointed by it. I think I would feel...

Interviewer: It is interesting what you just did. You sat back and you put your arms across your chest and would not look at me.

Interviewee: Yes, I hated that.

Interviewer: So when you try to project yourself into that feeling for a lifetime, how much do you think it would affect your sexuality?
Interviewee: Oh gosh, that is a good question. I think a fair amount. I think about it. It has gotten a lot better, but I think I even said to him, I was like, “If this keeps up after we have kids, if I have a pancake and a ball, then I want to get something done to this one.” So clearly, it is not a big deal, maybe half a cup size difference, but it really bothered me. I think it would have an effect. If they looked bad and I felt like regardless if I had flesh there or fat there, if they looked bad, I’d probably be just as reminded of it every single day. To see a complete absence maybe does not speak to just looking different or lumpy or feeling like these are not attractive.

Interviewer: That is exactly it.

Interviewee: That is huge.

Interviewer: It is interesting when you explore the psychology of beauty, how much of an impact does that have on a woman’s overall self-esteem? How much does it impact her relationship?

Interviewee: Huge. That is huge. It is on my mind every single day. I mean, it is as simple as I was leaving the house today and I had on some really funny shoes because we are moving and we do not have all of our stuff with us. I thought to myself, “Oh my gosh, I wish he could see me in my heels. I look so much prettier than I do in my little shoes.” It was funny because we have been married for eight years. Why am I still thinking about that? But I do, I think about it every single day. My toenails are all chipped now. It is like, that is not cute, he is going to see that. We have been doing it for eight years, but what I am thinking is it is a psychological thing and that there are pretty girls everywhere and I better keep up. It is huge and it matters. It doesn’t NOT matter.

Interviewer: Do you feel like it is as much of an outwardly competitive element like, I have to keep up, or do you think that it is somehow part of the female psyche that does define an element of us? Is it more internal or external?

Interviewee: Well I can say for myself growing up literally from the gate, I was very confident. I had no comparison. I had beautiful friends and I was not ever comparing. I was not asked to dances very first, but I just felt really pretty. It did not really matter. I think for me it is I am very blessed to have an internal kind of confidence, but then college hit and now it was kind of like, oh, college. There are all these girls and we are all partying and I am kind of like I am in this relationship, so it kind of turned into a got to keep up, with the girls. Since then, I think college is just its own experience because I am back to feeling naturally confident without much of that comparison.

Interviewer: So, if there was not another woman on the face of the earth, would it change the way you dress, the way you take care of yourself or what?

Interviewee: It would not, and that means it is internal. Because you look in the mirror and you are the only one in the mirror. If you feel like, I look dumpy or I look pale today, that is what is going to override it.

Interviewer: In my case it was early hysterectomy, loss of hair, hormones and then a prophylactic mastectomy, and yet I still wanted to come out on the other end and wear a bikini and feel good in it. It was so important to me.
Interviewee: Yes, I would never think that about you, by the way. If I was going to make an outward assumption, I would be like, she has totally got it all together, and my gosh, she is super blessed. And you are like, “I have been through a lot...” That is really interesting. If I can say it without overstepping my boundaries, I would just look at you and just be like, “man, she is like a Barbie. She has it all put together.” And you are like, “well Barbie has been through a lot.”

Interviewer: That means a lot to me. I really appreciate that.

Interviewee: I mean it.

Interviewer: Because more than anything, what I wanted to do is to set a new voice and a new face that could say, “you can do this.” Because what is heartbreaking is when women are so afraid of treatment, they do not save their lives. They are so afraid that if they give themselves over to the treatment, they will come out on the other end and not be someone they can recognize.

Interviewee: In this interview, I started thinking what would it be like the night before a surgery? Like looking at them for the last time would be like they are not going to be the same. That is huge. I would definitely break down. It is a relationship you have with your body from puberty and then definitely into like your sexual adulthood and then it is like your last night with them is really odd I am sure.

Interviewer: It is, and it was also hard the night before the hysterectomy. I will tell you something I find very beautiful on a philosophical level. It was not the time in my cycle for a period, but the night before I went into surgery for the hysterectomy, I had my period. It started. I thought that was so beautiful actually. It was like the last goodbye. I just thought that was gorgeous. I felt like it was like a part of my body like closing down, kind of expressing itself one more time.

Interviewee: It was like probably your first one.

Interviewer: Exactly, the connection, like that my body, like we were in it together. That is something I think a lot of women do not access. Since it is like a connection to their physical self. So you are right, there is an acknowledgment of laying something on the altar, like giving something up in exchange for your life. There is a sense of that that you go through. You are right like when you said, “I am thinking about like what is it like the night before.” There is a belief that carries you. My surgery was preventative. I had an 87% risk for breast cancer. I had survived ovarian cancer and I have two children. There really was not an option because I could not risk my children. But you stand at the crossroad of, “am I going to give up my femininity in exchange for their lives?” And you are willing to do it because these are your children, but it is a huge crossroad. So to try to salvage both is something, that for me, I felt was huge.

Interviewee: You can see why you are doing this... Like the story you were saying with the woman who chose not to have anything done and she passed away. That is one way to look at it, but if there are options, there are many better, better ways to look at it.
Interviewer: And to be able to make sure that that does not happen again for someone, that they can look at another person and say, “You have been through all that, then I can do this to save my life.” That is the thing I most want this program to set forth -- a statement of hope, a statement of possibilities. Yes, you suffer. Yes, you give up some things. Yes, it is hard. Those are all indisputable facts, but you can come out on the other side and that is the most important message.

Interviewee: I already feel it. I mean I feel it from you, I feel it from the information. This has dramatically changed -- I have not thought much about it until the last 24 hours when I started thinking about it. Then in our conversation, what I have learned from you, oh my gosh, how is this not something that is more known? The way you frame it is particularly important because what you are saying is just like you just said. It is horrible, it is awful, it is the ultimate scary thing, cancer is, but to know your options and to be empowered to come out on top in the way that you chose to, you get a little bit of a say in what you want the next 50 years to look like.

Interviewer: It is true. I used to say, “I have a vote in this.” I believe that all the way down to your faith, I think having faith -- I should not have said all the way down. I think it is the blanket for everything.

Interviewee: Yes.

Interviewer: I honestly believed that God had his hands on my life and that my road was unfolding, but that I was being called to take steps out there into the unknown, which was very, very difficult. But I felt that nobody was going to tell me when to die. I mean, that was not their call to make. No one was going to tell me, “you are alive; life, that is good enough”, because the way I defined “alive” was not being broken. I wanted more than that. But I think, to your question, you said, “Why is this not better known? This does not make sense...” One is we have to go back to “permission for beauty”, permission to ask for beauty, that beauty is not vanity, but it is just a natural element of a woman. Number two is the right to our sexuality. You are talking about culturally sensitive issues. So, they translate over... when you have been diagnosed, you are still dealing with that...

Interviewee: That is exactly what I talked about with my husband last night. I said to say, “You are lucky to be here”, well we are all lucky to be here... So when I said that, and we were unpacking the kitchen and talking about it, I said, “That is a really crass thing to say. I can never say that again...” If ever I said it, I cannot say it again, because you realize what you are saying. You are basically devaluing life a little bit for that person like, here are the crumbs, you are lucky you got them. Yes, I think from a spiritual aspect, vanity is of course a sin and vanity is not good, but beauty...

Interviewer: I think we have mixed up the issue.

Interviewee: They are different. They are entirely different.

Interviewer: They are. Think about it -- the Bible spoke of beauty as a positive. Even with Job, the last verse of the story, and “Job’s daughters were the most beautiful in all the land...” Like this was a blessing. So, beauty the blessing versus beauty the curse; it is a very different element. We do not think beauty should be the primary focal point in one’s life, but I think it is
part of the female psyche.

Interviewee: I think that God created that for a reason... I did not create myself. Thank God for that. It is often fearful for me. Why would I ever trash something that God has given me? I think I have a very spiritual view of my body. I think God made me look a certain way for a reason. People have told me before, I had an interview for my first job and I got the job. One of the girls told me you were the prettiest candidate. I was like, that was a little weird. I think God gave you your looks, dark hair, light hair. They are round or they are thinner. You may be that way for a reason. I have really wide hips. So I got a little attitude to go with it. I think my body has really kind of defined who I am.

Interviewer: That is interesting. That is a really interesting statement. When you lose an element of your body, how important it is?

Interviewee: It is. Honestly, I will tell you what, before the conversation, before the interview, I am really glad we talked yesterday because I got a chance to think about it. My attitude was, you are lucky, so why do you mess with it. That is not the attitude to have. I feel blessed that we talked about this and I can actually leave here and feel much more informed and gosh, a better woman, a better person for it.

Interviewer: Thank you, that means a lot to me.

Interviewee: Your work is really working. Yes, I really mean that.

Summary

Both population groups placed a very high degree of importance on the visual outcome in breast reconstruction. They felt their breasts were an expression of their femininity and were deeply wounded by the loss of their breasts, or the thought of the same. Again and again, respondents, in both groups, ranked an optimal visual outcome as critical to the overall healing process, and many expressed concern that emotional impact a woman would experience without such an outcome would actually lead to recurrence of the disease.

Both groups considered a need for self-perceived beauty to be a core element of a woman’s psyche, and all became passionately engaged when considering whether a physician might withhold full disclosure of various reconstruction techniques based on the physician’s personal preference for a certain method. Emotions around this topic were noted on a scale of five to ten, with one respondent bursting into tears when imagining a diagnosis of breast cancer without an immediate disclosure of all of the options available to her in breast reconstruction. When asked to explore her intense emotional response, she expressed that she had naturally assumed a physician would share all techniques available to her, whether he could provide them or not, and let her decide what to pursue.

Overall, participants placed a significant focus on the need for media, support groups, social media and other available avenues to make information regarding breast reconstruction available.
to women. They noted that the Komen Foundation, which most considered a primary source of information, offered little to no information on breast reconstruction. They asked the question “What about us? We have to go through this while they find a cure?”

A discussion with a teenage girl gave a unique perspective of the relationship women have with their breasts... boldly, she described her body... “breasts are different than any other part of your body... they feel different from fat in other places... (giggle) my friend (redacted) said it perfectly... she said, breasts are butter...’ it was perfect... they are butter! (laughter) you know, butter is the best ingredient in cookies, on bread, in all the recipes... it’s what makes something special... see, breasts make our bodies special...”
Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process
SECTION III

Section Three reflects the views of physicians as they explore the need to raise the bar for women facing breast reconstruction. This section was created utilizing a transcript provided by Dr. Pat Maxwell from the ALLERGAN ACADEMY® - Panel Discussion Transcript “Advances in Breast Reconstruction: Improving Patient Outcomes.” The original transcript is the property of Allergan Academy.

Physician’s Comments

1: Visual Outcome and the Emotional Health of the Patient

Summary

Panelists identify gene positive or high risk patient populations as key drivers of advancement in reconstruction. The importance of visual satisfaction to a patient’s ability to move forward after cancer is repeated by several respondents. Nipple-sparing mastectomies, and the need to ensure the general population understands its proven low risk, are noted several times. Panelists recognize that various techniques offer the opportunity for patients to “look even better after cancer.”

Corroborating Comments

“Experience is evolving because of the increased collaboration with doctors and also with the recognition of the prophylactic mastectomy patient, the patient at high risk, and/or the gene positive patient… We are aiming for solutions in which we all sort of disappear in the end, and we fade out into the background, and the patients are stepping beyond the stigma of cancer and actually doing something that we all really want them to do, and that is to be healed of this disease, so it goes away, and they can get on with their lives.”

“One of the leaders in Atlanta came up to me and said, ‘Why are you talking about this?’ Talking about nipple-sparing mastectomy about five years or so ago, and I said, ‘Because it is coming.’ It works, the data shows it is safe, it is such a change in terms of cosmetic results and patient enthusiasm for what they get.”

“… we are seeing patients now that have these nipple-sparing procedures, whether they are therapeutic or prophylactic, but especially those that are therapeutic, they actually have had treatment for cancer, and they end up with breasts that aesthetically are better than they started with, and we disappear because they get on with their lives.”

“… now the data is beginning to be collected around the world about how safe it is, because in terms of effectiveness, you can’t argue with it, almost a scar-less mastectomy, and a very high success rate, and the data is accumulating in fact that the safety is very, very good. That the recurrence rate in the nipple is virtually zero and that the recurrence rate and cure rate in the breast is, we believe, about the same, but the aesthetic outcomes and the emotional response for the
patients is just huge, but it was only five years ago where plastic surgeons were saying, ‘Why would we be doing this? We are not sure it is safe’, and so just think how fast that has changed.’

“We are seeing younger and younger women, we are seeing the high risk patient who is having bilateral prophylactic mastectomy disease, their demands for excellence in terms of their outcome has changed, they are educated, they are on the internet, they come in with all the information that is required, and they are demanding that sort of increased excellence in terms of the way that they are treated, so for us, I think that has been one of the biggest drivers, to all of the things that we are going to discuss today in terms of improvement and outcomes with breast patients.”

“… It started with the gene positive patient…”

“… What is pushing the surgeons who are reluctant to do it is the patients are saying, ‘I want that, and tell me why I shouldn’t have it.’”

“… 80% of the patients who are gene positive would get a nipple-sparing mastectomy because the data supports it, and because they can see the difference. They are talking to each other, and they are younger…”

“… It is just great gratitude, satisfaction and enjoyment from seeing what by teaming up, working together, simpler, less-invasive techniques, and better cosmetic outcomes, how patients can get back to life…”

“… Coordinating the efforts in preparing patients for either nipple-sparing mastectomies or areola sparing mastectomies, is allowing us to move the conversation beyond reconstruction to really almost aesthetic enhancement for the patient who has cancer, and so we are moving the dialogue. We are switching from merely reconstructing and restoring to actually healing them, making the cancer operation go away…”

“… once the process goes on, they start off thinking, ‘I just want to get this cancer out of my body,’ and by the time we were done with the chemotherapy, particularly the cancer patients now, their frame of reference is changing a little bit, and patients almost start to open up to the idea of, ‘Well, maybe I want this (or that) result’…”

“… it is hard to underestimate the smile factor there for the patient, because it is like, ‘I had this process, yeah, it was sort of horrible, but look what I got in the end, and I got a little trimmer, a little fuller, softer, nicer’…”

“I would sort of echo the two-stagers here and I am very firmly in that camp, I like a couple shots at it… I like, first of all, the emotions are settled down… once the patient is no longer afraid they are going to drop off the face of the earth, they start to relax a little bit, and in the post-operative period they can say, ‘Well, I was thinking I just wanted to be alive, but now I am thinking I want to be alive and I want to be really good. So I really want to thrive, not just survive this procedure, so maybe we could enhance this a bit’…”

“… you talk about turning into, ‘I don’t want to die for my cancer,’ to, ‘I really appreciate what you have done for me, doctor,’ …it is this whole paradigm shift to turning it to a cosmetic result…”
“... more and more, when I walk into see them, they are smiling because they got something good out of all of this, and it includes all these things we've talked about, and the fat grafting and the fact that they got a little fat removed from where they don't want it and they got it to smooth out the irregularities in their reconstruction, particularly up here, where no flap or implant really solves that problem...”

2: Evolutionary Process to Adopt Newer Procedures

Summary

Panelists recognize the significant lag time between advances in techniques and acceptance of those advancements by referring physicians. It is well noted that women are unnecessarily penalized by the slow speed, and many endure traditional interventions when more advanced options are available.

Respondents note the importance of validating the efficacy and safety of the advanced procedures, and recognize the importance of these advances to women. They acknowledge the superiority of these procedures over traditional ones, and acknowledge the impact of the results on QOL.

Corroborating Comments

“... Getting from the scorched earth era to the better aesthetic, best oncology era, is really tricky. We start out with really very well-formed habits; very hard to change those, even if you go to a conference and you hear about new techniques, seeing those get put into practice is a little bit harder...”

“... maybe because of the new generation of breast surgeons, (there is) a willingness to challenge preconceived ideas...”

“... I think the goal here is to describe some techniques, have surgeons present them, validate that they work, to validate that they don't cause a higher recurrence rate, and if we can do that, just think about how many women will be spared wound complications and disfigurement as part of the cancer treatment...”

“I became an advocate, having seen patient after patient go through this and have such an easier time than we had before... plastic surgeons are, in our community at least, are embracing it, but gradually. They have a lot of concern, (but) there is a change...”

“... lots of care, lots of focus on enhanced blood supply, thinking about antibiotic prophylaxis, appropriate antibiotic prophylaxis for these patients, the use of drains, there are a number of advances, they are small advances, but the big advance is the concept...”

“... we are thinking about all the steps, we are not accepting the steps in the way they were handed down to us by our forefathers, but we are actually re-examining things...”
“All of these advances are tied to collaboration and if we don't have the concept that we have greater reliability and communication with our general surgeons, that we are obtaining mastectomies with high quality flaps, predictable flaps, if you don't have that, you can't take these advances of inserting better devices, different devices, acellular dermal matrix... it has to work all in conjunction, and I think it is the collaboration that has driven the advances that we have been able to make throughout this whole process…”

“... we've been at it for about seven years, and sometimes I question myself, ‘so do I really think this makes a difference, maybe I could go back to what I was doing before’ and I have to tell you, when I ask myself that question, there is no way I'm going back because it is a different operation…”

“We tend to underestimate donor sites, but I can tell you... among women plastic surgeons, if they got to choose what kind of reconstruction they would have, this was done in a survey, 70 percent would have an implant... Because they don't want to have a big operation…”

“It is about control, it is about enhanced soft tissue drapery, and it is about crafting a result that is individualized, that is stylistically beautiful, that is symmetrical, these are things that we all wanted to do before with our older techniques, but we really couldn't quite get there…”

“… in the end, it is not really about 'it was really cool and fun to do this sophisticated operation with tissue transfer and microvascular techniques...' I don't think the operation is about me, it is about them, and so, the plastic surgeons that are in the know, and they are women, are saying, 'I wouldn't want to have an autologous tissue reconstruction'.”

“… it is all about getting a great result for the patient, and now we can do it. We can do it in a way with the tools that we didn't have yesterday, but we have them today…”

“…there is a more powerful argument for this type of approach because it is changing the way I practice medicine…”

“I think if you can get past the awkwardness of the plastic surgeon showing the breast surgeon something, that it is very helpful.”

“... we have all done a lot of subcutaneous mastectomies through the years... I used to do more lateral approaches in that operation years ago, and that evolved... so it was just the extension of that experience and those techniques that evolved to be successful, taken to a next higher degree of oncologic finesse…”

“Similarly, working with my breast surgeon, he was struggling to do these minimal incisions, I said, 'Why don't you just inject the breast?' All of the sudden the hydro-dissection made the plane so much easier and he was like, 'this is genius,' but it is just a simple step, one that we might take, we don't really take it as anything of great advance, but we each help each other, and that is what makes the patient have a better outcome.”

“... if we did direct implant reconstructions, we'd be getting paid about half of what we get paid for an expander, and I would actually have to give it much more personal attention than I currently do.”
“... the first few times the patient came in and she had had some fat grafting, usually it was to smooth this upper part of the breast, she would feel a little something there. And we could look on ultrasound and see a little area that was very homogeneous, and yet she felt something, we could see something, do we need to biopsy that, I've got two choices. I can just do a biopsy or I can call the plastic surgeon and say, ‘Did you do a little fat grafting right here?’ ‘Oh, yes we did.’ And this is perfectly consistent, so do you need to educate the radiologists, and the surgeon, about what they might see there...?”

3: Devices Pros & Cons

Summary

Panelists express a need for extra high profile implants in the reconstruction patient, and the benefits of such to the aesthetic outcome. Respondents acknowledge the significant improvements offered through acellular dermal matrix, and cite a reduction in pain in post mastectomy patients when dermal matrix is used. Several respondents identify a need for suture tabs, on currently available expanders, to ensure symmetry and lower pole stabilization.

Corroborating Comments

“The exciting thing that has happened over 15 or so years has been the advancement in technology, the advancement in tissue expanders, the new types of implants that are available to us that sort of let us custom select our approach to each individual patient.”

“... in Canada, we've had access to using shaped 410 implants for a number of years, and that has really changed what we can provide women.”

“I would suggest that about 65 to 70 percent of the women that I am doing post-mastectomy reconstruction will be with a highly cohesive shaped device.”

“... what has been interesting to me in that context is high profile implants in the mastectomy patient are the equivalent of a moderate profile implant in an augmentation patient... so we are actually doing high profiles, almost the default choice, and occasionally these extra high profile implants, which I am using more and more in the last year or two... I have recognized that even with the high profile implant we are not getting quite the projection we want, and patients, when we mention it, actually get kind of excited about it. We have a fair number of patients who really, when we bring up the idea of the extra high profile implant, they really like it...”

“... with the tissue matrix and all the skin, all of the sudden you can use high profile, extra high profile implants, they work great...”

“... The extra projecting round are the Allergan style 45, so that implant, to have extra projection, because it is a standard gel, a standard cohesive responsive gel, is that implant has to have a narrower base to get the extra projection. But in breast reconstruction, the volumes are usually quite large, therefore, the base works fine and you get the extra projection, so it is almost a unique situation and opportunity to use that particular device, and then with the regenerative additives we have, we actually are thickening the soft tissue cover, so we take away some of the previous challenges of implant fold issues by extra fill, extra projection, and regenerative touch ups...”
“… now that the patients can have the dermal matrix do the same job, they have a lot less pain, they seem to be getting through this with a lot less... I won't say morbidity, but difficulty, as you said, we sort of get a little bit less in the foreground in their experience as they go through this, they get through this a little bit easier…”

“One advance leads to another advancement or change, and I think that one of the things that we have all debated is, because we are creating, there is less of a raw surface, there is more potential for, in lower height devices, more of a potential for shifting... Now all of the sudden we have created a new problem, because the lower height device with the smooth surface on top of it may shift, and so we don't have perfect symmetry and this is incredibly important in bilateral cases, where we want perfect symmetry, correct? So the next advance is to consider suture tabs for our expanders, so that we got it just the way we want it, and it stays that way…”

“… one innovation alters another, so the addition of the acellular dermal matrix, which has the beautiful advantage of better pocket preparation, we can now do it immediately the way we used to do it delayed, by releasing the origin of the pectoralis like we do with an aesthetic case, but that area, that lower part, where the ADM engages the expander, there is no adherence... So therefore, only the part of the expander superior where the bio-cell can interact with the muscle has the opportunity to adhere. So as we use medium to shorter height expanders, or vertically more ADM, there will be less tissue adherence. So therefore, there is the need for lower pole finesse stabilization, so I think the addition of the suture tabs to the 133 expander series is a big addition, one that wasn't necessary without ADM, but one that enhances outcomes with ADM.”

“… the concept of the higher profile device acting like, in essence, a mid-range profile device in an aesthetic patient is a very important point, because we all know that although we are working toward an aesthetic operation, they are really not exactly equivalent, the breast has been removed, there is more scarring, there is always going to be a bit more contracture around these devices, so you really do need this extra projection to craft a result that we can feel very comfortable with…”

4: The Value of Collaboration

Summary

Panelists recognize the expansion of collaboration between breast and plastic surgeons as setting the speed of advancement in reconstruction. The interdependency of oncologic and reconstructive skills in breast reconstruction is identified as the core element behind optimal visual results.

Examples of shared techniques, resulting in improved outcomes, are offered by several respondents. These techniques, along with advances in acellular dermal materials, implant design, and fat grafting have led respondents to conclude implant reconstruction is, most often, the best option. Recognition is given to the collective impact that occurs when these techniques are combined.

Corroborating Comments
“… I think, I felt like I had a big jump in my technical approach when Pat (Maxwell) would come in, early in the case, and one of the things he saw was my work trying to get that subcu off of the anterior mammary fascia without traumatizing the flaps. He said, ‘Well, let me show you a little technique here,’ and it turned out, in my mind, to be what is done by plastic surgeons all the time with a facelift, a sort of a facelift technique, so that you can reach, without traumatizing the flaps, areas that you otherwise might have stretched the tissue too much…”

“… I think, unfortunately, right now, there is way too little consultation; there is way too little thought. The patient is ready, the diagnosis is made, we have decided what operation, okay, go see the scheduler and I will think more about this in the operating room, and we need an oncoplastic pause at that scheduling moment, when that breast surgeon is scheduling the case, where that surgeon says, ‘Where is the tumor?’ maybe even draws it on the skin, ‘What is my surgical plan?’ and, I am going to send this patient to the plastic surgeon and say, ‘this is my plan, is that a good plan, do you have any advice?’”

“… many times, the plastic surgeon has some ideas that we can learn from…”

“… I think we all agree that every good breast reconstruction begins with a good mastectomy. Good mastectomy being defined by optimal oncologic treatment and at the same time, optimal aesthetic planning and technical carrying out of the operation…”

“I heard across Britain is that 45% of the breast reconstructions are done with latissimus flaps -- 45% -- whereas, in the United States it is probably less than 5%. And you have to ask yourself why. And the reason why is because in the hands of the surgeons working by themselves, that is about the level of their comfort, their comfort zone. But clearly in the U.S., we know that a latissimus flap is not the right operation for almost half the patients, that there are lots of other operations which are just as good, or probably better, in terms of quality of results and morbidity…”

“… different patients get different procedures based on their needs…”

“… our capsule contracture rate is as low or lower than it is cosmetic breast augmentation, which is crazy…”

“When we were training, we were all trying to come to the clavicle, the latissimus, maybe the edge of the ribs, the middle of the sternum, that is not the limits of the breast, and so we have adjusted, over the last several years, and I think most breast surgeons have moved in this direction, to saying ‘what are the limits of this gland in this patient?’ and marking those prior to the operation so that you do a proper resection of the breast gland, and not the ‘scorched earth out to the limits’ approach that we learned in the beginning…”

“I think where we are seeing the biggest advance really is something that wouldn't jump off your screen as the most exciting technology, but it is the collaboration between plastic surgeons and breast surgeons.”

“… now we've learned to talk before, during, and after, and I think we are really seeing patients benefit from that extended collaboration…”

“… we are coming out of our silos…”
“… traditionally plastic surgeons have just sort of taken whatever the breast surgeon gave them and done the best they could, and our message to breast surgeons is, do the best oncology, but think about how to facilitate that plastic surgeon's work so that that patient has a better outcome…”

“… I am almost an oncologic surgeon, at this point. When I see these patients, I am helping to decide whether they are going to have a mastectomy or a lumpectomy, I am helping to decide whether they are going to have nipple-sparing or not nipple-sparing, I am helping to decide whether they are going to have a unilateral or a bilateral mastectomy…”

5: Varying Techniques in Advanced Mastectomies

Summary

Panelists described the value of several advanced techniques, along with their ideal application and expected benefits. It becomes clear that, even within the world of AMT, there are varying methods, and combinations of methods, that ensure each mastectomy a uniqueness of its own; the determination of the technique, and/or combination used, appears to be dependent on the needs of the patient, and the comfort level of the surgeon.

Corroborating Comments

“… the really large breasted patients who are young, without much ptosis, in a few of those we are doing a lateral, sort of a lazy-curved lateral, but the fact that we have to do a sentinel node incision for many of these patients allows us to reach some areas that really would be almost impossible from a pure inframammary approach…”

“… as the breasts get larger, the operation will shift to a skin reducing pattern mastectomy and reconstruction or to a non-total mastectomy reduction pattern…”

“… there are more patients being done now with devices and with the help of things like acellular dermis, and with fewer patients being done with the traditional latissimus flap or TRAM flap in the United States…”

“… they no longer need any skin, now they just need content. Implants can provide content pretty much as well as flaps, but smaller operations, no donor site morbidity, less surgical risk, and all that… I am just going to bring up this issue of using this acellular dermis material now, which I think has helped kind of do what the latissimus flap did, it helps hold the device in place, and then we used devices instead of flaps… all of the sudden the patient has an operation that is getting to be pretty similar to a cosmetic operation, for the reconstruction, and they go home the next day or sometimes the same day, so that has been… these things are sort of additive, so we have the nipple-sparing procedure, so we don’t need skin, we don’t need a flap necessarily, unless the patient wants it, and now we have a tissue matrix to provide the role of like a flap to support the device…”

“… you are putting a large prosthetic device into a field that theoretically is contaminated with bacteria, because the breast is colonized with bacteria… this makes it so I’ll stop, take a pause, and really think about what we are doing here, with regard to improving the outcome and potentially avoiding some of the complications that we have traditionally seen with not only overt infection, but, perhaps, even with capsular contracture…”
“... my two enemies at the moment are tissue necrosis and infection, and those are the things that we are really trying to zero in on and that requires good surgical technique in terms of tissue necrosis, in trying to figure out where these infections are coming from...”

“... the device removal rate for infection and this concept of skin-sparing, nipple-sparing, tissue matrix surgery, is about three percent. It runs about three percent in most of the published studies, and the infection rate is about double that, maybe six percent. Well, we’ve got to get that device removal rate down to under one percent, because those three percent of patients is three percent too many...”

“I want to go back to the regenerative tissue matrix, because I think that has been one of the biggest advancements that has fostered more minimal access, less surgery, and makes for better device outcomes...”

“... it is sort of this engineering with tissue breast reconstruction, so what is great is for the patients who need it or want it, they can get a microvascular reconstruction with something that is very slick, but now they can also get a reconstruction that is pretty similar, maybe even better in some cases, cosmetically, with a lot less surgery...”

6: Increased Need for Measurements/Validation

Summary

Panelists acknowledge an increasing body of data establishing the efficacy and safety of nipple-sparing implant reconstruction. In earlier sections, respondents recognize time delays in this data reaching the ‘field’ to ensure referral sources are aware of the findings.

Respondents identify the importance of media and wide spread messaging to close the gap in awareness in both referring physicians and women facing reconstruction.

Corroborating Comments

“... raise the bar in terms of defining better techniques and then validating them, getting more universal acceptance across the spectrum in the United States and even internationally as to what works best. So getting people to face up to the fact that there are things being done that are better somewhere else that they need to raise their skill set to that level...”

“... people now have to really believe that what you are doing is best...”

“... exposure and media awareness of these things is what is going to drive it sooner or later, once we validate it...”

“... I think we do have to validate that these things really are correct, that they get better cosmetic results, and that patients are emotionally better off, and that the cancer treatment is the same, or better...”
“… there really is increasing data that there are constant publications coming out from centers around the U.S. and around the world that really are validating the success of these outcomes…”

“We have a series submitted, I think it is 225 breasts, as I recall. Nipple-sparing, combining our experience with that of Dr. Allen Gabriel in Washington, that is submitted for presentation and publication in the Spring, and I think you called me, and I called Allen, to re-look at the data, because there were zero tissue expanders lost to infection in that series…”

“I know you are enthusiastic about the inframammary incision, I have been pretty reluctant to go that route, mainly because I think it puts an additional challenge on the breast surgeon to do something they are not familiar with, but it is possible, and I think this is where science and evidence will take us, that it is possible that the rate of nipple loss and nipple necrosis will actually be lower with that incision…”

“Emotionally, if your surgeon is willing to embark, your breast surgeon is willing to embark on this road, the first thing at the end of the operation that they will notice is, if they are successful, they have made a much thicker flap than they are used to feeling, especially if they have used a tumescence technique, but even so, the flap feels thicker at the end… that means they have made a good flap… they are going to be anxious at that point, this is a little different, am I putting this patient at some risk? So my advice to those surgeons is take a sample of that flap. Pick the thickest part you can find, take a sample there, and send that as an anterior margin. I have been doing that for a long time, it never comes back with any breast tissue in it, it is subcutaneous tissue…”

“The good news also is we now have increasing data, on long-term results with the presence of ADM around devices, as well as these newer devices themselves that are giving long-lasting non-encapsulated implant reconstructions…”

“… as we validate outcomes, we measure what we have done, there are so many steps involved, this isn’t just the mastectomy and just the implant, just the regenerative matrix, it is the combination of these, so we have to, one, have each step be reproducible, be validated, and then look within that and write down the subsets and see what it is that is giving these collective improvements, because I do think it is the collective improvements…”

7: Raising the Visual Standard

Summary

An improved standard of care would include the willingness of breast surgeons to include plastic surgeons in decisions PRIOR to surgery, and referral sources to consider individual patient needs when making a recommendation. There is not a consistent understanding of the visual results that can be achieved in a mastectomy, and this affects referral patterns. Since it appears a large number of referring physicians believe the visual outcome of a mastectomy is fairly consistent among surgeons, there is no motivation to refer a patient outside of their ‘social’ network.
Corroborating Comments

“… for every place that does it well, there are maybe nine places that aren’t doing it as well. So to get this adopted around the country is pretty exciting…”

“… it’s the concept of recognizing that every breast cancer patient needs to be thought of as an aesthetic breast patient as well, and how can we get the best aesthetic outcomes for someone who has to undergo treatment for disease of her breast…”

“… It is a learning process to move from that old school of dermal thickness flaps to the new school where we are really lifting the subcu off of the anterior mammary fascia, and that is I think the real difference in our thinking…”

“… I think one of the concepts that has been raised here, not only collaborating in communication, but actually collaborating in the operating room because that gives you an incredible insight into the challenges of removing the breast cancer safely, we are pushing you, the breast doctors, to work through tiny incisions, but it allows us to see where the challenges are, so we can design our operations better, around incisions and for proper removal of breast tissue without compromising the aesthetic outcome and, in fact, enhancing the aesthetic outcome…”

“… there is a real desire from educational programs to political organizations, to we as individual surgeons to move together in a collective, collaborative fashion, to really push the needle…”

“… State of New York, I think they have just passed a law, that every woman who is facing a mastectomy is required to have a plastic surgery consultation…”

“… The challenge, I think, is educating others in your field, with the things, the concepts and the techniques that you now grasp and advocate…”

“The way things move forward, in breast care, in general, is so fast, that if we begin to try to educate breast surgeons in all of the latest plastic surgical techniques for breast reconstruction, they are going to be practicing state of the art from about ten years ago, or 15 years ago…”

“…changing practice is really difficult. All those habits, you get busy, you do the same thing you always did before, and we really want to see a change in practice. We really want to see sort of like a pause, so that the surgeon thinks of the oncoplastic aspects of the case as much as anything else…”

“… now we can make people look like they have had cosmetic surgery because we can support their implants with this tissue matrix and we have got all their skin and life goes on…”

“I was asked to give a talk on pedicle TRAM flaps, so I pulled out of my file of the talk I gave at that meeting six years ago on pedicle TRAM flaps and I showed it, and I said, ‘But I don’t do this anymore,’ and then I showed inframammary approach, nipple-sparing mastectomy with ADM tissue expander, followed by some second stage things, and I made the comment that I view… jokingly a little bit... I view an acellular matrix, when you open up the sterile bag, as a latissimus in a package…”
“... it is really amazing how advancing techniques have done what every patient wants, and we want to do... that is to minimize surgeries, less trauma, less access, faster recovery, and I think we are on a track working together with our breast surgical colleagues of certainly raising the bar at the moment...”

“... now you are starting to turn this reconstructive procedure into a cosmetic procedure...”

“... I was talking to one of our breast surgeons about reporting some skin necrosis after mastectomy and the breast surgeon said, 'We don't report that;' and I thought, 'Well, why not? It is a complication'."

“The fact we are leaving all the skin on these breasts means that you have got to up your game in order not to have skin necrosis. It was easier when you just resected all the skin of the breast, you didn't have to worry about flap necrosis, you have bigger flaps, you have to improve your technique...”

“... whatever you are doing today, probably five years from now you are going to be doing something a little different, and you have to be open to newer ideas that get validated, that get shown to raise the bar a little bit more...”

8: The Multi Prong Strategy

Summary

Participants note the desire of women to help other women facing the same challenges, and the importance of providing survivors with ways to tell their stories. The need to establish measurements to validate the superiority of AMT is recognized by the participants, as well as is the need to standardize expectations for mastectomies in the minds of the referral sources.

Two interesting findings were noted in the comments of the participants that reflect a lack of standardization even among the top surgeons: 1) one surgeon commented on the use of fat grafting to improve the look of a woman in a bathing suit, and 2) another referred to his inability to oversee all details, or interact with the general surgeon due to his responsibilities at a teaching hospital. MA provides results and care beyond these comments noted and this distinction is an important element to be included in the strategic plan.

Corroborating Comments

“How do we continue to measure outcomes, validate the findings from these techniques, the clinical findings in addition to the aesthetic, so that we can really further this, so it becomes more mainstream, so that more or most oncologic breast surgeons will accept the information, the data, and the option? Not that every patient should have it, but the option. “

“We’re all reporting our own experience, and that is compelling to some extent, but the people will continue to say, ‘That is only in this center or that center, and who knows how those patients were selected,’ so the leadership of the American Society of Breast Surgeons is developing a registry for patients having nipple preserving mastectomy operations and I think that registry will allow an
experience all over the country through the program that the American Society of Breast Surgeons has called Mastery of Surgery or Mastery of Breast Surgery. That is a data quality management program that many of us are plugged into already, and we are looking at a program including nipple preserving mastectomy as part of that, so a broad-based, somebody said 1,000 miles wide and this deep, so we see what is happening everywhere instead of just at specialized locations. “

“... those patients who are actually wanting other women to know of the opportunity, and how they have weathered the storm and are back living, I think as more and more individual connections and stories get out, at that level, that in addition to the important data collection will further the cause...”

“It is so important to these patients. I mean, we tend to diminish, oh well, cosmetic outcome, ‘you are alive honey, be happy for that.’ These women, they are very passionate about this, about getting their life back, and so the first thing is, they are passionate about living, yes. But the second thing is, when they look back and they say, ‘Gosh, I felt that I was about to go through something horrible, and be disfigured and lose my identity,’ and they have gone through and gotten a nipple preserving mastectomy, the next thing they want is to go and tell everyone what happened, and tell everyone it is not true, you don't have to end up not recognizing yourself, not feeling whole anymore, you get to be whole again. They are very passionate about this, and it is an important quality of life issue for them, and I think, if we diminish that, acting as if oncology is the only thing and who cares about how you look, I think, we really don’t understand those patients.”

“At the moment we are running a trial, back at home, that is a randomized trial looking at outcomes, both in terms of complications and patient satisfaction in one-stage versus two-stage acellular dermal cystic reconstruction, so hopefully within a year or year and a half we will have the results of our trial and that will add at least a little bit more information to this discussion.”

“I'm at a University Hospital, I have residents and fellows, they get to do a lot of the surgery with me, I can't scrub with the general surgeons, I don't have time, so the residents and fellows help me get those cases done, I often come in at the end of the case, so for me, the model of trying to direct implant would require much more personal attention to each of those cases, which I can't give it.”

“What I think is going to be challenging is measuring the aesthetics. As we all know, that is... the subjective aspect of it is we can't underestimate that, because that is what the patient is taking away. They don't really care whether it costs five dollars or ten dollars; they just want to be as good as they can be at the end of the operation.”

“So you do the exposed area of the breast, which is the one... no one sees the other part, it is this part that they see, but now they can wear a blouse or a swimsuit and look normal or better than normal, so I think it has been one of those pieces in the last five years that has just made a huge difference and it is just so widely accepted now in the United States, it is actually almost crazy, whereas ten years ago, very few people were doing it.”

“We have been working with some advanced imaging technology, and have been applying it more to breast reconstruction and when the patient is imaged, when they come in the office after their mastectomy with expander in place, they may have a good start toward the expansion, but then go ahead and simulate in that first visit, they select their final implant. All of the sudden they have a much better attitude toward the process, but we are seeing, Scott, just what you said and Jim what you said, as then they approach the second operation, we re-image them, they re-look at their simulated desire, and it is usually a little more projection, a little more volume, we can adjust, we
can get a little soft tissue thickness, it is the fat grafting, and they really become involved in a way, as you said, of moving back into life and leaving us alone. So it is pretty exciting, you can really document that in terms of the process and the outcomes.”

“I think a very good point that I never really considered is it truly is the exposed areas of the breast that the patients can now show, because now they have got a soft transition from their collarbone right down to the top of the breast, perhaps better than they ever had it in their life, and we have taken them now and we have moved them away from their cancer, and that is what we are here for. To help them get over this whole process. It is not treatment, it is healing... moving on.”

“We are experiencing better patient outcomes in this important era, we are experiencing better patient outcomes in this important field. And in fact, things will continue to evolve and perhaps we can convene here a year from now and talk about the things that we have advanced or seen during the year, how we have measured the outcomes, how we work closer together, how we are planning operations, improving device usage, and hopefully improving the whole area of women's health.”

9: One Stage Vs. Two Stage

Summary

The majority of panelists recognize expanders as a vital tool in achieving optimal results, though many recognize a competing need to keep healthcare costs down by minimizing surgeries. Overall, respondents define a limited patient profile as the ideal candidate for a one stage reconstruction, and most recognized the ‘two stage’ as offering technical and patient adaptation opportunities.

Corroborating Comments

“...at least in the healthcare environment where cost is such a critical issue, the ability to potentially provide patients with a direct implant single-stage reconstruction with the use of ADM and an implant has just opened the box tremendously to what we can offer to patients.”

“I think those patients, (one-stage breast reconstruction) have to be very carefully selected, it is certainly not right for everybody, and I recognize and understand the benefits of having a tissue expander and having the ability to make adjustments and changes in a second procedure, in many cases, that is exactly what I do... But I think in the properly selected patient, the patient who has an A or B cup breast, good quality tissue, minimal to no ptosis, has reasonable expectations, does not want to be overly large in terms of her reconstruction, we can quite predictably now, in a single stage, through nipple-sparing or skin-sparing mastectomy with the use of acellular dermal matrix, provide beautiful, single-stage reconstructions.”

“...In our healthcare environment, the cost savings of doing that in a single procedure, without the recurrent visits to hospital or to clinic for expansion or for a second surgical procedure, in a single device, it makes just an enormous difference. It is certainly not right for everybody, there are still many patients where we will use a tissue expander in affiliation with an ADM, but in that properly selected patient, I think the results can be outstanding.”
“Well, I’m not a big fan of direct implant, but I do think, first of all, it is critical for those who are going to do it, that they pick the right patient, and the right patient is bilateral, nipple-sparing ideally, or skin-sparing symmetrical mastectomies, where the breast surgeon is plugged into the idea that the mastectomy has to be one that can be followed by an implant, meaning that it can’t get too far beyond the margins of the breast, and particularly the inframammary and lateral folds are more or less 25 respected, so if that all happens, that could work.”

“What I feel pretty strongly about is if you took ten consecutive direct implant reconstructions, and ten consecutive similarly controlled two-stage reconstructions, that the two-stage patients will look better, how much better is debatable, but I think on average, they are going to do better, because you have the chance to fine-tune the result.”

“So many of my patients, we have so much else to talk about, I just don’t think it is the right time to be talking, do I want to be a style 20 high profile or style 45 extra high profile, do I want to be a B-cup or a C-cup, and what I find is a lot of patients upstage what they want as the process goes on. They start off saying, ‘I just want to be the same as I started,’ and by the time we finish, they say, ‘Well, actually I wouldn’t mind being a C-cup, I started out as a B, but this is my present to myself for having breast cancer, or having to do this’.”

“I have been a long-time advocate of two-stage breast reconstruction. I think all of us here have been, and while I agree that there are certain patients that are appropriate considerations for considering direct implant, the reasons that I think two-stage are important is number one, I think we really reduce complications on the front-end, two, I think that we are able to plan better now our options working together with breast surgeons, knowing the final implant we will be selecting, as we select the expander and the expander has a certain plan, it will create an environment along with the regenerative matrix, that will enable us in the second stage to really create that final outcome…”

“… I think we all work, now, to make breast reconstruction more like breast augmentation. We interface breast aesthetics between the reconstructive, the revisionary, and the aesthetic, and I think the principles we are using are all becoming the same, and frankly, I think the devices and the techniques are becoming the same. So I like to take the opportunity in that second stage to really enhance the outcomes, so for me, that is not just a capsulotomy and an implant, it is a pocket enhancement, whatever alteration that is. I generally add a second, thicker, regenerative material that further enhances that soft tissue and generally do fat grafting, and in other words, doing something that is more of... I call that a bio-engineered approach, but we are doing something more than just replacing a tissue expander with an implant, I think it is the combination of these things, in conjunction with the preserved nipple areola that really enables us to have better results that are longer lasting.”

“Even the surgeons who are pretty enthusiastic about direct implant reconstruction, a lot of them will go to the operating room also with an expander as a backup if they feel that for some reason it is not a propitious moment to do a direct implant, so in fairness, they do that.”

“We have kind of shown that if we can do 50 to 60 percent of our reconstructions direct to implant and 40 to 50 percent in two-stage, we can make it almost revenue neutral for the purchasing groups at the hospital.”
“There are patients who are not focused on volume that can be quite comfortable with (a one step)… ‘you have given me a nice result that is about what I have right now, and I will be content’…”

“The second issue is the issue of potential skin necrosis, if we go direct to implant I think we may see, and this was what you will show us, we may see that there is a higher rate of device removal, etc., because skin didn’t make it, we had to revise it, etc. The third component is that I look at the second stage as the refinement stage, this is where we can stop focusing so much on getting the cancer out now, we got the cancer out, now what we are going to do is actually make something absolutely beautiful. Or as beautiful as we can make it. And so from my standpoint, I need that second stage to get to that point.”

“As much as you would love to put fat in the first stage, that is not going to happen unless you are really pushing it, so we do a lot of fat grafting, and in fact, we are into the next phase of figuring out fat grafting for the breast… it has been going on for over ten years, I think everybody believes now that it works, to some degree, in everybody, except maybe the severely radiated patient… it enhances every kind of reconstruction, whether it is a flap reconstruction or a device reconstruction, and you need a second operation to do it… you are not doing it in the first operation, so the fat grafting becomes a wonderful tool, now we are trying to figure out a couple things regarding fat grafting, one is how to do it most efficiently, how to do it most effectively, and really the interesting one is what are the economics of fat grafting, because we have just started looking at that.”

Sincere thanks to Allergan for allowing the recoding of the original transcript for the purpose of providing added insight to this study.

**My Own Story**

My story carries a dual perspective as it has given me the chance to view the realities of breast reconstruction from the perspective of a woman who fought for her personal sense of beauty, and a researcher who analyzed the obstacles presented by the medical world, and society at large. My heart’s mission is for my own struggle to “go for good” for the benefit of others. Dr. Pat Maxwell has brought extraordinary skills, devotion and support to this subject and, together, we have shared the unique opportunity to see the world from the other’s eyes.

I was diagnosed with ovarian cancer in 2008, and have been blessed beyond measures in my recovery. At the end of treatment I learned I was BRCA1, and immediately began researching options for reducing my high risk of breast cancer. I began this process immediately upon learning my BRCA status and found it very interesting to navigate the world both bald, and with a cancer history that intimidated many doctors during consultation.

I was told “You are most likely to die from ovarian cancer; why have a mastectomy?” And, when I fought for a nipple-sparing procedure, I was told I was “vain”. There was a general perception that I should “accept my fate” and not worry about such frivolous subjects as beauty, for, from the world looking in, I was just lucky to be alive. From my interior world, the view was entirely different. In my world, there was the woman I was fighting for and bringing her back to wholeness was the strongest vote I could offer to her future.
When Dr. Maxwell reviewed my case, I found a partner in my journey and I was told, with confidence, that despite my previous breast surgery I was a candidate for a nipple-sparing procedure and a very visually pleasing outcome. My vision for myself, to be whole and fully restored, became the only vision in the room -- gone was a story of defeat -- that day I became a woman with a life ahead of her who was worth the application of great effort, for I was a woman with a future.

It is important to say here that I was two years out from ovarian cancer at my first stage of the PM -- my CA125 was four which signaled complete remission (now four years out with a CA125 of two). I had done a great deal of work to ensure my body was strong, and there were no unnecessary chances taken with my health. What is even more precious to share is that I underwent a very aggressive mastectomy with implant reconstruction, in Dr. Maxwell’s hands, and all of my skin, nipples included, survived perfectly. And with each step of the reconstruction process, I watched a woman emerge who I recognized; yes, she was different, softer in some ways, stronger in others, and physically more than she once had been, and that turn of events always made me believe God smiled.

What is beauty to a woman? So many times I have asked this question, attempted to articulate it for those who have tried to diminish it. I have asked this in what has become a comparative study of women who have faced breast reconstruction, women without such an experience, and physicians who, every day, stand in a position to affect the quality of a woman’s life with their understanding of the answer.

There is a gap in our societal grasp of the meaning of beauty, and in that divide many women’s lives are affected. So often noting beauty with importance is considered a trite act, and never does this prejudice do more damage than when a woman has lain down her sense of beauty to protect her life; for in that act, she has so often chosen to protect her children, and her mate, at the cost of her core of femininity.

Yes, there are those who argue that femininity is not defined by the exterior, and in large part we all agree, but for those who are visually oriented, who see our bodies as an expression of our wholeness, ripeness, as a woman, that need is not broken by culturally imposed shame, it is only suffered silently as we become trapped between two dynamic forces -- the driving need to restore external beauty and the disdain of those who judge it.

As I have interviewed many women I have often posed the question of, “What was your first thought at the time of diagnosis?” Over and over, it is the same reply; “I thought, ‘Am I going to live?’” And what am I going to look like?” The backstory to this answer primarily resonates in the desire for body confidence, sexuality and the ability to move forward after cancer without reminders of its happening. I have been awarded the status of sojourner in a little understood battle for life and have been given permission to ask questions that expose, explore and bring forth new understanding.

A single woman, who was not sexually active and very conservative in her demeanor and dress,
spoke of the importance of her breasts to her naked reflection in the mirror, sharing the depth of shame she felt even when she was the only one who knew what didn’t exist underneath her clothing...

Another described an instance in which she stood applying makeup, dressed in nothing but a t-shirt and panties, only to catch her husband watching her with a familiar hunger in his eyes—her soft giggle, and repeat of the moment, revealed how cancer was a thing of the past and her sexuality an expression of the future...

Yet another described the shame of a failed reconstruction, which left her misshapen, and how she felt her lack of overall beauty caused the original surgeon to have little interest in a revision. This patient went on to describe how Dr. Maxwell restored her and her words came forth unexpectedly as she said, “He picked ME; he helped ME... I know I’m not a pretty woman...”, and with a coy smile and deepening voice, “but I feel pretty now...”

Over and again, in fact 100% of the time, those interviewed stated their sense of beauty as having the upmost value in their overall healing; they describe it as “vital to their health and ability to move forward after cancer...” New mothers, post cancer, described the package of femininity wrapped up in pregnancy and breasts and how the absence of their breasts would have left the picture incomplete. There is a joy and exuberance in the women who are fulfilled by their outcome in breast reconstruction, and an emptiness and hollow sound in those who attempt to describe a visually disappointing one.

Most importantly, much too often, referring physicians are described as “placing little value on the visual outcome”, “having little knowledge of the advanced reconstruction techniques available” and “having a negative opinion about the nipple-sparing procedure”, despite the obvious value of all of these to the quality of life for many patients. AND referring physicians often admit to having little knowledge of the efficacy of advanced procedures, such as the nipple-sparing technique, while they admit to discouraging their use though they may well meet many patients deep rooted need for a specific visual outcome.

In the completion of this first stage of the study, we find ourselves faced with the call to elevate the importance of beauty in the healing process without defining it in the same way for every patient. Surely, it is the woman’s right to determine the definition for herself and if scars and the
absence of a breast signify an expression of her internal vision, more power to her fight... But for those of us who find our feminine core best revealed in the soft curves and fullness of our breasts, who see the darkened shade of our nipples as being as unique as the color of our eyes, we are due the effort and knowledge that would keep these elements alive...

... For that is truly what we battle for -- LIFE -- to remain connected to the evidence of life found in clear cancer follow-ups as well as in the giggle of a confident woman who reaches for her husband... in the joy of a woman who sits by the pool at ease in her skin... and in the gratitude of one who carries the knowledge that she was found worth the effort... For we begin this journey as a fight to save ourselves and in the course of it, we fight to save each other...

_Tamarin_...
Addendum A

Curriculum Vitae
G. Patrick Maxwell, M.D.

PERSONAL STATISTICS:
Date and Place of Birth: July 15, 1946 Selma, Alabama
Citizenship: USA
Address: (Office) 2020 21st Avenue South, Nashville, Tennessee 37212

PRESENT APPOINTMENTS:
Founder, Aesthetic Surgeon, Maxwell Aesthetics, Private Aesthetic Clinic, Nashville, Tennessee
2008 Founder, Plastic Surgeon, Nashville Plastic Surgery, Private Practice, Nashville, Tennessee
1981 – 2008 Director, Postgraduate Plastic Surgery Fellowship
1988 – Present, Clinical Professor of Surgery, Department of Plastic Surgery, Loma Linda University Medical Center, Loma Linda, California
2008 Assistant Clinical Professor, Department of Plastic Surgery, Vanderbilt University, Nashville, Tennessee
1985 - Present, Oversee Vanderbilt Rotating Plastic Surgery Residents
1989 - Present, Founder, Chairman, Allergan Academy, Irvine, California
2005 - Present, Founder, Chairman, Inamed Academy International, Santa Barbara, California
2003 – 2005, Co-Founder, EVP & Chief Surgical Officer. Diversified Surgical Institutes (DSI), Nashville, Tennessee

EDUCATION:
B.S. - 1968 Vanderbilt University
M.D. - 1972 Vanderbilt University School of Medicine, Nashville, Tennessee

PROFESSIONAL TRAINING:
1972 - 1973, Internship - General Surgery, The Johns Hopkins Hospital, Baltimore, Maryland
George D. Zuidema, M.D. - Chief

1973 - 1975, Residency - General Surgery, The Johns Hopkins Hospital, Baltimore, Maryland
1975 - 1979, Residency - Plastic Surgery, The Johns Hopkins Hospital, Baltimore, Maryland

**FELLOWSHIPS:**
3/1976 - 7/1976, Microvascular Surgery, R. K. Davis Medical Center, University of California, San Francisco, California

1/1978 - 7/1978, Hand Surgery, Raymond M. Curtis Hand Center, Union Memorial Hospital, Baltimore, Maryland

**PREVIOUS TEACHING APPOINTMENTS:**
3/1979 - 6/1979, Instructor, Division of Surgery, The Johns Hopkins Hospital, Baltimore, Maryland

8/1979 - 8/1981, Assistant Professor, Department of Plastic Surgery, Eastern Virginia Medical School, Norfolk, Virginia

6/1981 – 6/1983, Clinical Attending, Department of Plastic Surgery, Nashville City Hospital, Nashville, TN

6/1981 – 1985, Clinical Instructor, Vanderbilt University School of Medicine, Nashville, TN


**AWARD AND HONORS:**
Omicron Delta Kappa, Vanderbilt University, 1968

Mosby Award for Scholastic Achievement, Vanderbilt University Medical School, 1972

Lang Award for Academic Excellence, Vanderbilt University Medical School, 1972

Best Paper (Reconstruction Category), American Society for Plastic and Reconstructive Surgeons, Senior Resident's Conference, Dallas, Texas, 1979


James Barrett Brown Award (Advancement of Knowledge in the Field of Plastic Surgery), Presented at the Annual Meeting of the Association of Plastic Surgery, Scottsdale, Arizona, 1980

**SCIENTIFIC EXHIBIT AWARD:**
Post-mastectomy Breast Reconstruction, Virginia Medical Society Annual Meeting, Williamsburg, Virginia, 1980
Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process

Walter Scott Brown Award (Best Video Presentation), American Society for Aesthetic Plastic Surgeons Annual Meeting, Washington, D.C., 1984

Walter Scott Brown Award (Best Video Presentation), American Society for Aesthetic Plastic Surgeons Annual Meeting, Los Angeles, California, 1987

Walter Scott Brown Award (Best Video Presentation), American Society for Aesthetic Plastic Surgeons Annual Meeting, San Francisco, California, 1988

Scientific Poster Exhibit Award (with Drs. Frank Barone, Jack Fisher, and Larry Perry), American Society for Plastic and Reconstructive Surgeons Annual Meeting, San Francisco, California, 1989

Chul Song Award for Philanthropic Service, American Society for Aesthetic Plastic Surgery, 1996

Presidential Award, American Society of Plastic Surgeons, 2005 - “for excellence as an educator and innovator, bringing art and science… to a new level for the specialty”

Congressional Recognition of Merit in recognition of his visionary contributions to plastic & reconstructive surgery, service to others and revolutionary developments impacting survivors of breast cancer, September 2007

**BOARD CERTIFICATIONS:**
National Board of Medical Examiners, Parts I, II and III, American Board of Plastic Surgery

**SOCIETY MEMBERSHIPS:**
American Society of Plastic and Reconstructive Surgeons
American Society for Aesthetic Plastic Surgery
American Association of Plastic Surgeons
Southeastern Society of Plastic and Reconstructive Surgeons
The Association of Plastic and Reconstructive Surgeons of South Africa (Honorary)
The Japan Society of Plastic and Reconstructive Surgery
The Canadian Society of Plastic Surgeons (Honorary Member)
American Society for Reconstructive Microsurgery
International Society of Reconstructive Microsurgery
International Association of University Plastic Surgeons
American College of Surgeons
American Medical Association
Nashville Academy of Medicine
Tennessee Medical Association
Florida Society of Plastic Surgeons (Honorary Member)
The Johns Hopkins Medical and Surgical Association
Canby Robinson Society
ACTIVITIES:
Plastic Surgery In-Service Training Exam: Basic Principles Committee Member, 1979, 1980
Aesthetic Committee Chairman, 1981
ASPRS: Video Committee, 1988 - 1992
ASAPS: Public Education Committee, 1988 - 1994
ASAPS: Education Commission - Videotape Co-Chairman, 1989 – 1993
ASPS: Media Breast Spokesperson, 1990 - 1994
ASAPS: Ultrasound-Assisted Liposuction Task Force, 1995 – present
Founder & Director: The Institute for Aesthetic & Reconstructive Surgery at Baptist Hospital, 1989 – 2004
Medical Advisory Board, Form & Figure Magazine, 1999
Co-Founder & Principal: Integrative Aesthetics Skin Care Company, 2001
Inamed Academy, Co-Founder and Chairman, 2003 – present

PRESENTATIONS BY INVITATION:
2. Third Annual Axial and Myocutaneous Flap Workshop, Norfolk, Virginia, June, 1979
3. Plastic Surgery and Grand Rounds, University of Louisville, Kentucky, February, 1979
4. Axial and Myocutaneous Flap Symposium, Newark, New Jersey, November, 1979
6. Primer Curso Sobre: Colgajos Axiales, Musculares y Musculocutaneous, Mexico City, Mexico, January, 1980
7. Visiting Professor: Case Western Reserve University, Cleveland, Ohio, February, 1980

Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process


10. Reconstructive Urological Workshop, Norfolk, Virginia, April, 1980


15. Visiting Professor, University of Tennessee, Memphis, Tennessee, August, 1980

16. Guest Speaker, New Jersey Society of Plastic Surgeons, Dennis, Massachusetts, September, 1980

17. Program Panel, American Society of Plastic and Reconstructive Surgeons Annual Meeting, New Orleans, Louisiana, October, 1980


20. Post-mastectomy Breast Reconstruction Symposium (ASPRS Educational Foundation), Princeton, New Jersey, October, 1980


23. Joseph L Yon Annual Trauma Symposium, Portsmouth Naval Hospital, Portsmouth, Virginia, March, 1981

24. Eighth International Conference on Hoffmann External Fixation, San Juan, Puerto Rico, April, 1981

26. Guest Speaker, State of Virginia Reach to Recovery Annual Meeting, Richmond, Virginia, April, 1981

27. Visiting Professor, Saint Barnabas Hospital, Livingston, New Jersey, May, 1981

28. Sixth Annual Axial and Myocutaneous Flap Workshop, Norfolk, Virginia, June, 1981

29. Guest Speaker, American Cancer Society Breast Carcinoma Symposium, Danville, Virginia, June, 1981

30. Clinical Frontiers in Reconstructive Microsurgery (ASPRS Educational Foundation), Anaheim, California, June, 1981

31. Fifth Annual Flap Dissection Workshop, Norfolk, Virginia, June, 1981


33. Cancer Symposium, Post-mastectomy Breast Reconstruction, Jackson, Tennessee, October, 1981


37. Multidisciplinary Microsurgical Symposium, New Orleans, Louisiana, February, 1982

38. Guest Faculty, Plastic Surgery Instructional Course Symposium, Chicago, Illinois, March, 1982

39. Guest Speaker, Breast Reconstruction Seminar, American Cancer Society Program, Volunteer General Hospital, Martin, Tennessee, April, 1982

40. Visiting Professor and Guest Speaker, Harvard Medical School, Boston, Massachusetts, April, 1982
41. International Symposium on Reconstructive Microsurgery, Presbyterian Hospital, Oklahoma City, Oklahoma, May, 1982

42. Sixth Annual Flap Dissection Workshop, Norfolk, Virginia, June, 1982

43. French Association of Maxillofacial Surgeons, Tours, France, June, 1982

44. Guest Faculty, Muscle and Musculocutaneous Flap Symposium of the University of California, San Francisco, California, August, 1982


47. Visiting Professor, St. John's Mercy Medical Center, St. Louis, Missouri, January, 1983

48. Guest Faculty, Plastic Surgery Instructional Course Symposium, Atlanta, Georgia, March, 1983

49. Aesthetic Aspects of Reconstructive Surgery Panel, American Society for Aesthetic Plastic Annual Meeting, Los Angeles, California, April, 1983

50. International Congress on Breast Reconstruction, Brussels, Belgium, May, 1983

51. Seventh Annual Flap Dissection Workshop, Norfolk, Virginia, June, 1983


53. Post-mastectomy Breast Reconstruction Instructional Course, American Society of Plastic and Reconstructive Surgeons Annual Meeting, Dallas, Texas, October, 1983

54. Guest Speaker, Rhode Island Female American Medical Society Annual Meeting, Providence, Rhode Island, May, 1984

55. Visiting Professor, Brown University, Providence, Rhode Island, May, 1984

56. Guest Speaker, New Jersey Medical Society Annual Meeting, Atlantic City, New Jersey, May, 1984

57. Guest Speaker, Dayton Surgical Society, Dayton, Ohio, May 1984

58. Eighth Annual Flap Dissection Workshop, Norfolk, Virginia, June, 1984
59. Guest Faculty, International Breast Symposium, Jerusalem, Israel, June, 1984

60. Guest Faculty, Plastic Surgery Instructional Course Symposium, Houston, Texas, June, 1984


62. Guest Speaker, Association of Operating Room Nurses Annual Congress, Dallas, Texas, February, 1985

63. Visiting Professor, Parkland Hospital, Texas Southwestern Medical School, Dallas, Texas, February, 1985

64. Guest Speaker, Central Texas Cancer Symposium, Austin, Texas, April, 1985

65. Ninth Annual Flap Dissection Workshop, Norfolk, Virginia, May, 1985


67. Guest Speaker, Houston Society of Plastic Surgeons, Houston, Texas, March, 1986

68. Visiting Professor, Department of Plastic Surgery, St. Luke’s Hospital, Houston, Texas, March, 1986

69. Post-mastectomy Breast Reconstruction Instructional Course, American Society of Plastic and Reconstructive Surgeons Annual Meeting, Los Angeles, California, October, 1986

70. Breast Reconstruction Panel, American Society of Plastic and Reconstructive Surgeons Annual Meeting, Los Angeles, California, October, 1986

71. Guest Faculty, Thirteenth Annual Post Graduate Course in Plastic Surgery, Northwestern University, Chicago, Illinois, December, 1986

72. Guest Faculty, Southeastern Society of Plastic and Reconstructive Surgeons Symposium: Breast Reconstruction, Atlanta, Georgia, January, 1987


74. Tenth Annual Flap Dissection Workshop, Norfolk, Virginia, June, 1987

75. Guest Faculty, Eighth Post-graduate Instructional Course in Plastic and Reconstructive Surgery for Australia and New Zealand, Sydney, Australia, September, 1987
76. Guest Faculty, The Australian National Update in Plastic Surgery Meeting, Sydney, Australia, September, 1987

77. Guest Faculty, Breast Panel, The World Congress of Surgery, Sydney, Australia, September, 1987

78. Guest Faculty, Plastic Surgery of the Breast: State of the Art, Santa Fe, New Mexico, September, 1987

79. Guest Speaker, Harris Methodist Fort Worth Medical Center, Fort Worth, Texas, October 1987

80. Guest Faculty, North American Society of Lipolysis Annual Meeting, Atlanta, Georgia, November, 1987

81. Post-mastectomy Breast Reconstruction Instructional Course, American Society of Plastic and Reconstructive Surgeons Annual Meeting, Atlanta, Georgia, November, 1987

82. Guest Faculty, 14th Annual Post Graduate Course in Plastic Surgery, Northwestern University, Chicago, Illinois, December, 1987


84. Guest Faculty, Southeastern Society of Plastic and Reconstructive Surgeons Symposium: Breast Reconstruction. Atlanta, Georgia, January, 1988

85. Visiting Professor, Tulane University, New Orleans, Louisiana, February, 1988


88. Guest Faculty, Lipoplasty Society of North America Regional Symposium, Indianapolis, Indiana, May, 1988

89. Guest Faculty, Third International Congress on Plastic and Reconstructive Surgery of the Breast, Brussels, Belgium, June, 1988

90. Eleventh Annual Flap Dissection Workshop, Norfolk, Virginia, June, 1988

91. Guest Faculty, Plastic Surgery of the Breast: State of the Art, Santa Fe, New Mexico, September, 1988
Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process

92. Visiting Professor, New Jersey College of Medicine and Dentistry, Newark, New Jersey, September, 1988

93. Guest Faculty, North American Society of Lipolysis Annual Meeting, Toronto, Canada, October, 1988


95. Liposuction Panel, American Society of Plastic and Reconstructive Surgeons Annual Meeting, Toronto, Canada, October, 1988

96. Guest Speaker, Tennessee Academy of Family Practice Physicians Annual Meeting, Gatlinburg, Tennessee, November, 1988

97. Guest Faculty, 15th Annual Post Graduate Course in Plastic Surgery, Northwestern University, Chicago, Illinois, November, 1988

98. Guest Faculty, Southeastern Society of Plastic and Reconstructive Surgeons Symposium: Breast Reconstruction, Atlanta, Georgia, January, 1989


100. Guest Faculty, Advances in Plastic Surgery Symposium, Snowbird, Utah, February, 1989

101. Guest Faculty, Aesthetic and Reconstructive Breast Surgery Symposium, Washington University School of Medicine, St. Louis, Missouri, March, 1989

102. Guest Faculty, National Breast Symposium, St. Mary's Hospital, Grand Rapids, Michigan, April, 1989

103. Guest Faculty, Johns Hopkins Breast Reconstruction Symposium, Baltimore, Maryland, May, 1989

104. Visiting Professor, New York University, New York, New York, May, 1989

105. Guest Faculty, Manhattan Eye and Ear Symposium on Cosmetic Surgery, New York, New York, May, 1989

106. Guest Faculty, Twelfth Annual Flap Dissection Workshop, Norfolk, Virginia, June, 1989

108. Guest Faculty, Plastic Surgery of the Breast: State of the Art, Santa Fe, New Mexico, September, 1989

109. Visiting Professor, University of Louisville, School of Medicine, Louisville, Kentucky, September, 1989

110. Guest Speaker, Kentucky Medical Association, Louisville, Kentucky, September, 1989

111. Visiting Professor, University of Kentucky, School of Medicine, Lexington, Kentucky, September, 1989


113. Guest Speaker, Nassau Surgical Society Breast Symposium, Garden City, New York, December, 1989


117. Guest Faculty, Mt. Sinai and Beth Israel Hospitals Breast Surgery Symposium, New York, New York, May, 1990

118. Panel Member, Breast Reconstruction, Southeastern Society of Plastic and Reconstructive Surgeons Annual Meeting, Kiawah Island, South Carolina, June, 1990

119. Guest Faculty, European College of Oncology's International Breast Symposium, Venice, Italy, June, 1990

120. Guest Faculty (Co-Chairman), PSEF Breast Symposium, Santa Fe, New Mexico, September, 1990


124. Guest Faculty, Aesthetic Surgery of the Breast Symposium, University of California, San Francisco, California, March, 1991

125. Guest Faculty, Comprehensive Breast Cancer Symposium, Williamsburg, Virginia, April, 1991

126. Guest Faculty, 21st Annual Canadian Aesthetic Surgery Symposium, Toronto, Canada, April, 1991


128. Guest Speaker, Japan Society of Plastic and Reconstructive Surgery, Matsumoto, Japan, May, 1991


130. Guest Faculty (Chairman), PSEF Breast Symposium, Santa Fe, New Mexico, August, 1991

131. Guest Speaker, John Staige Davis Society, Annapolis, Maryland, September, 1991


135. Guest Speaker, Symposium on Breast Cancer, Baylor University Medical Center, Dallas, Texas, September, 1991


137. Guest Speaker/Surgeon, Academic Hospital, Gent, Belgium, November, 1991

138. Guest Speaker/Surgeon, Florence Nightingale Hospital, Duesseldorf, Germany, November, 1991
139. Guest Speaker/Surgeon, Frauenklinik Rheinfelden Hospital, Rheinfelden, Germany, November, 1991

140. Guest Speaker/Surgeon, St. Markus Krankenhaus Hospital, Frankfurt, Germany, November, 1991

141. Guest Speaker/Surgeon, Centre Hospital of the University of Marseilles, Marseilles, France, November, 1991

142. Guest Speaker, Teleplast Symposium, San Diego, California, December, 1991

143. Guest Speaker/Surgeon, European School of Oncology International Breast Cancer Symposium, Milan, Italy, January, 1992

144. Guest Faculty, Baker-Gordon-Stuzin Symposium on Cosmetic Surgery, Miami, Florida, February, 1992

145. Guest Speaker, International Society of Plastic Surgery Congress, Guadalajara, Mexico, March, 1992

146. Aesthetic Breast Surgery (ASAPS Instructional Course), American Society for Aesthetic Plastic Surgeons Annual Meeting, Los Angeles, California, May, 1992

147. Guest Faculty, Aesthetic and Reconstructive Breast Surgery Symposium. Manhattan Eye, Ear and Throat Hospital, New York, New York, May, 1992

148. Guest Faculty, PSEF Breast Symposium, Santa Fe, New Mexico, August, 1992

149. Guest Faculty, Southeastern Society of Plastic and Reconstructive Surgeons Symposium: Breast Reconstruction, Atlanta, Georgia, January, 1993

150. Visiting Professor, University of Massachusetts, Worcester, Massachusetts, February, 1993

151. Aesthetic Breast Surgery Update (Instructional Course), American Society for Aesthetic Plastic Surgery, Boston, Massachusetts, April, 1993

152. Guest Speaker/Surgeon, Queen Victoria Hospital, East Grinstead, United Kingdom, June, 1993

153. Guest Faculty, 7th Congress, European Section of the International Confederation for Plastic and Reconstructive Surgery, Berlin, Germany, June, 1993

154. Guest Faculty/Surgeon, Behring-Krankenhaus, Berlin, Germany, June, 1993

155. Visiting Professor/Surgeon, University Clinic Grosshadern, Munich, Germany, June, 1993
156. Visiting Professor/Surgeon, Petofi Sandor Hospital, Budapest, Hungary, June, 1993

157. Visiting Professor/Surgeon, Clinica Dermatologica Umberto I, Rome, Italy, June, 1993

158. Visiting Professor/Surgeon, Casa di Cura Villa Cherubini, Florence, Italy, June, 1993

159. Visiting Professor/Surgeon, University Clinic Sahlgrenska, Gothenburg, Sweden, June, 1993

160. Visiting Professor/Surgeon, Inselspital, Bern, Switzerland, June, 1993

161. Guest Faculty/Surgeon, 10th International Symposium for Plastic and Reconstructive Surgery, Clinica Planas, Barcelona, Spain, June, 1993

162. Visiting Professor, St. Francis Hospital, Toledo, Ohio, August, 1993

163. Guest Faculty, PSEF Breast Symposium, Santa Fe, New Mexico, August, 1993

164. Guest Speaker, Brazilian Congress of Plastic Surgery, Curitiba, Brazil, November, 1993

165. Guest Speaker, Georgia Society of Plastic Surgeons, Atlanta, Georgia, November, 1993

166. Guest Faculty, Southeastern Society of Plastic Surgeons Breast Symposium, Atlanta, Georgia, January, 1994


168. Aesthetic Breast Surgery Update (Instructional Course), American Society for Aesthetic Plastic Surgery, Dallas, Texas, April, 1994

169. Panel Member, American Society for Aesthetic Plastic Surgery, Dallas, Texas, April, 1994


172. Guest Faculty, International Symposium on Breast Surgery, Sao Paulo, Brazil, June, 1994

173. Guest Speaker, Michigan Academy of Plastic Surgeons, Mackinac Island, Michigan, July, 1994

174. Co-Chairman, PSEF Breast Symposium, Santa Fe, New Mexico, August, 1994
175. Faculty and Panel Member: ASPRS Annual Meeting, San Diego, California, September, 1994

176. Guest Faculty, Congreso Iberolatinoamericano de Cirugia Plastica, Vina del Mar, Chile, November, 1994

177. Guest Faculty, Southeastern Society of Plastic Surgeons’ Breast Surgery Symposium, Atlanta, Georgia, January, 1995

178. Faculty and Panel Member, Symposium on Cosmetic Surgery, Miami, Florida, February, 1995

179. Faculty and Panel Member, American Society of Aesthetic Plastic Surgery Annual Meeting, San Francisco, California, March, 1995

180. Guest Faculty, Symposium on Aesthetic Surgery of the Face, San Francisco, California, March, 1995

181. Guest Faculty, 11th Congress of the International Confederation for Plastic, Reconstructive and Aesthetic Surgery, Yokohama, Japan, April, 1995


183. Guest Faculty, Aesthetic Plastic Surgery of the Face, Eyes, Nose, Scalp & Neck, Newport Beach, California, July, 1995


185. Guest Faculty, PSEF Breast Surgery Symposium, Santa Fe, New Mexico, August, 1995

186. Guest Faculty and Panel Member, American Society of Plastic and Reconstructive Surgeons’ Annual Meeting, Montreal, Canada, October, 1995

187. Guest Speaker, Northeastern Society of Plastic and Reconstructive Surgeons, Boston, Massachusetts, November, 1995

188. Guest Faculty, 32nd Brazilian Plastic Surgeons’ Annual Meeting, Brasilia, Brazil, November, 1995

189. Guest Faculty, Southeastern Society of Plastic Surgeons’ Breast Surgery Symposium, Atlanta, Georgia, January, 1996

190. Guest Faculty, Horizons in Aesthetic Surgery, Monterey, California, February, 1996


193. Guest Faculty, Body Contouring Symposium, Lake Tahoe, Nevada, June, 1996


195. Guest Faculty, PSEF Breast Surgery Symposium, Santa Fe, New Mexico, August, 1996

196. Chairman, Emerging Practice Conference II, Nashville, Tennessee, September, 1996

197. Guest Faculty, Aesthetic Plastic Surgery Symposium, New York, New York, October, 1996

198. Guest Speaker, Northeastern Society of Plastic Surgeons, Washington, DC, October, 1996

199. Guest Faculty, Italian Society of Plastic & Aesthetic Surgery, Perugia, Italy, October, 1996

200. Guest Faculty and Panel Member, American Society of Plastic and Reconstructive Surgeons Annual Meeting, Dallas, Texas, November, 1996

201. Guest Faculty, Southeastern Breast Symposium, Atlanta, GA, January, 1999

202. Guest Faculty, Canadian Society of Aesthetic Plastic Surgeons Annual Meeting, Toronto, CA, April 1999

203. Guest Faculty, Operating Surgeon, Dallas Aesthetic Surgery Symposium, Dallas, TX, May, 1999

204. Guest Speaker, International Society for Aesthetic and Reconstructive Surgery Biannual International Meeting, San Francisco, June, 1999

205. Guest Faculty, Santa Fe Breast and Body Contouring Symposium, Santa Fe, NM, August 1999

206. Thuess Lecturer and Visiting Professor, Stanford University, Palo Alto, CA, September, 1999

207. Guest Faculty and Operating Surgeon, Canadian Society of Plastic Surgeons Annual Meeting, Calgary, Canada, October, 1999
208. Guest Speaker, Panel Member, American Society of Plastic Surgeons Annual Meeting, New Orleans, LA, October, 1999

209. Guest Faculty and Operating Surgeon, Southeastern Society Breast Symposium, January, 2000

210. Guest Faculty, PSEF Advances in Plastic Surgery Symposium, La Jolla, CA, January, 2002


212. Guest Faculty, University of California, San Francisco, Aesthetic and Reconstructive Surgery Symposium, San Francisco, CA March, 2000

213. Guest Speaker, Operating Surgeon, Shanghai, #9, Peoples’ Hospital, Shanghai, China, March, 2000

214. Guest Speaker, Operating Surgeon, China National Hospital, Beijing, China, March 2000

215. Guest Speaker, Operating Surgeon, Guangzhou Military Hospital, China, March 2000

216. Guest Faculty, American Society Aesthetic Plastic Surgeons Annual Meeting, Orlando, FL, May, 2000


218. Guest Faculty, Italian-American Society of Plastic Surgeons, Newport, Rhode Island, June, 2000

219. Guest Speaker, European Symposium of Plastic Surgery, Barcelona, Spain, September, 2000

220. Guest Faculty, American Society of Plastic Surgeons Annual Meeting, Los Angeles, 2000

221. Guest Faculty, Dallas Plastic Surgery Symposium, Dallas, TX, March, 2001

222. Guest Faculty, Panel Member, American Society of Aesthetic Plastic Surgeons Annual Meeting, New York, NY, May, 2001

223. Guest Speaker, Canadian Society of Plastic Surgeons, Toronto, Canada, April, 2002

Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process

225. Guest Faculty, Italian-American Society of Plastic Surgeons, Ischia, Italy, June 2002

226. Guest Speaker, Operating Surgeon, Brazilian Aesthetic Surgery Meeting, Sao Paulo, Brazil, March 2003

227. Guest Speaker, New York Society of Plastic Surgery, New York, NY, April, 2003

228. Panel Member, and guest speaker American Society of Aesthetic Surgeons annual meeting, May 2003


230. Speaker Faculty, Italian-American society of Plastic Surgeons, Ischia, Italy, July 2003

231. Guest Speaker, World Congress of Aesthetic Surgery, Lindau, Bodensee, Germany, July, 2003

232. Guest Faculty, Santa Fe Breast Symposium, Santa Fe, NM, August, 2003


234. Guest Speaker, Canadian Society of Plastic Surgeons, November, 2003

235. Chairman, Inamed Academy, Newport Beach, CA, August, 2004

236. Guest Speaker, Canadian Society of Aesthetic Plastic Surgeons, Quebec City, Canada, September, 2004

237. Co-chairman, Inamed Academy Canada, Quebec City, September, 2004

238. Chairman, Inamed Academy, Hollywood, FL, November, 2004

239. Chairman, Inamed Academy, New York, NY, November, 2004

240. Chairman, Inamed Academy, Dallas, TX, November, 2004

241. Guest Faculty, European Oncoplastic Breast Symposium, Milan Cancer Center, Milan, Italy, December 2004

242. Guest Faculty, Milan Cancer Center, Milan, Italy, December 2005

243. Chairman, Inamed Academy, Maui, Hawaii, February, 2005
244. Chairman, Inamed Academy, New Orleans, LA, April, 2005
245. Guest (Keynote) Speaker, Chinese National Congress of Plastic Surgery, May, 2005
246. Chairman, Inamed Academy China, Guangzhou, China, May, 2005
247. Guest Speaker, Korean Society of plastic Surgeons, Gyeongju, Korea, May, 2005
248. Chairman, Inamed Academy, Korea, Gyeongju, Korea, May, 2005
249. Guest Speaker, Hong Kong Society of Plastic Surgeons, Hong Kong, May, 2005
250. Chairman, Inamed Academy, Sonoma, CA, June, 2005
251. Chairman, Inamed Academy Latin America, Mexico City, Mexico, July, 2005
252. Guest Faculty, “Masters Presentation,” Annual Meeting of the American Society of Plastic Surgeons, Chicago, IL, September, 2005
253. Chairman, Inamed Academy, Chicago, IL, September, 2005
254. Chairman, Inamed Academy, Houston, TX, November, 2005
256. Chairman, Inamed Academy, Washington, D.C., January, 2006
257. Guest Faculty, Advanced MATRIX course (plastic surgery) Marrakech, Morocco, March, 2006
258. Co-Chairman, Guest Faculty, Oncoplastic Surgery Course, American Society of Breast Surgeons, Baltimore, MD, March, 2006
259. Guest Speaker, Singapore Plastic Surgical Meeting, Singapore, March, 2006
260. Guest Speaker, Malaysian Society of Plastic Surgeons, Kuala Lumpur, Malaysia, March, 2006
261. Guest Speaker, Bangkok Plastic Surgical Group, Thailand, March, 2006
262. Guest Speaker, Vietnamese Plastic Surgical Society, Ho Chi Minh City, March, 2006
263. Chairman, Inamed Academy, Orlando, FL, April, 2006
Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process

264. Panel Member, American Society of Aesthetic Plastic Surgeons Annual Meeting, Orlando, FL, April, 2006

265. Guest Speaker, California Society of Plastic Surgeons Annual Meeting, Las Vegas, NV, June, 2006

266. Chairman, Inamed Academy, Las Vegas, NV, June, 2006

267. Panel Member, Southeastern Society of Plastic Surgeons Annual Meeting, Sea Island, Georgia, June, 2006

268. Chairman, Inamed Academy Latin America, Mexico City, Mexico, August, 2006

269. Guest Speaker, International Society of Aesthetic Plastic Surgeons, Rio de Janeiro, Brazil, August, 2006

270. Chairman, Inamed Academy, South America, Rio de Janeiro, Brazil, August, 2006


272. Chairman, Allergan Academy, San Francisco, CA, October, 2006


274. Guest Speaker, St. Vincent’s Hospital, Sydney, Australia, November, 2006

275. Guest Speaker, Australian Plastic Surgical Registrars, Brisbane, Australia, November, 2006

276. Guest Faculty, Aesthetic Surgery of the Breast, Second European Symposium, Milan Cancer Center, Milan, Italy, December, 2006

277. Guest Faculty, Southeastern Society of Plastic Surgeons Breast Symposium, Atlanta, GA, January 2007

278. Guest Faculty Northwest Society of Plastic Surgeons, Lanai, HI, February 2007

279. Chairman, Allergan Academy, Northwest Society of Plastic Surgeons, Lanai HI, February 2007

280. Chairman, Allergan Academy, American Society of Aesthetic Plastic Surgeons annual meeting, New York NY, April 2007
281. Guest Faculty, Oncoplastic Breast Surgery Symposium, American Society of Breast Surgeons annual meeting, Scottsdale AZ, April 2007


283. Chairman, Allergan Academy, at the California Society of Plastic Surgeons annual meeting, San Francisco, CA, May 2007

284. Panel member, American Society of Plastic Surgeons annual meeting, Baltimore, MD October 2007

285. Chairman, Allergan Academy, at the American Society of Plastic Surgeons annual meeting, Baltimore, MD, October 2007

286. Guest Faculty, International Master Course on Aging Skin (IMCAS), Paris, France, January 2008

287. Faculty, Allergan Academy International at IMCAS, Paris France, January 2008


290. Visiting Professor, Loma Linda University, Loma Linda, CA, February 2008

291. Guest Faculty, Oncoplastic Surgery Symposium as the American Society of Breast Surgeons annual meeting, New York, NY, April 2008

292. Panel Member, American Society of Aesthetic Plastic Surgeons annual meeting, San Diego, CA, May 2008

293. Chairman, Allergan Academy at American Society of Aesthetic Plastic Surgeons annual meeting, San Diego, CA May 2008


295. Keynote Speaker, on Oncoplastic Surgery, Rio DE Janeiro, Brazil, September 2008

296. Panel Member, American Society of Plastic Surgeons Annual Meeting, Chicago, IL, October 2008

Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process
297. Chairman, Allergan Academy, New York, NY, November 2008

298. Guest Faculty, “Live Surgical Demonstration” Southeastern Society of Plastic Surgeons, Breast Symposium, Atlanta, GA January 2009

299. Guest Faculty, “Surgical Demonstration” Baker Gordon Symposium on Cosmetic Surgery, Miami, FL February 2009

300. Guest Faculty, The Royal and Ancient Society of Plastic Surgeons, Sea Island, GA, April 2009

301. Guest Faculty, Oncoplastic Breast Surgery Symposium, San Diego, CA, April 2009

302. Guest Faculty, American Society of Aesthetic Plastic Surgeons annual meeting, Las Vegas, NE, May 2009

303. Keynote Speaker, California Society of Plastic Surgeons, Squaw Valley, CA, May 2009

304. Keynote Speaker, Johns Hopkins Medical and Surgical Association Biennial Meeting, Baltimore, MD, June 2009


306. Chairman, Allergan Academy at the Breast and BodyContouring Symposium, Santa Fe, NM, August, 2009

307. Panel Member, American Society of Plastic Surgeons Annual Meeting, Seattle, WA, October 2009

308. Faculty, Bioskills Lab, Mastopexy and New Concept Summit, LifeCell, Las Vegas, NV, November, 2009

309. Chairman, Allergan Academy Annual Meeting, Las Vegas, NV, November 2009

310. Keynote Speaker, Oncoplastic and Reconstructive Surgery of the Breast, Milan, Italy, December 2009

311. Guest Faculty, “Live Surgical Demonstration” Southeastern Society of Plastic Surgeons, Breast Symposium, Atlanta, GA, January 2010

312. Chairman, Allergan Academy at the Plastic Surgery Senior Residents Conference, Anaheim, CA, January 2010

313. Faculty and Keynote Speaker, BPS Surgeons Forum, Key Biscayne, FL, March 2010
314. Keynote Speaker, National Consortium of Breast Centers, Las Vegas, NV, March 2010
315. Faculty, American Association of Plastic Surgeons, Austin, TX, March 2010
316. Chairman, Allergan Academy at the Aesthetic Meeting, Washington, DC, April 2010
317. Faculty, American Society of Breast Surgeons, Las Vegas, NV, April 2010
318. Faculty, LifeCell BPS Bioskills Lab, Miami, FL, April 2010
319. Guest Faculty, American Society of Plastic Surgeons, Society for Women’s Health Research, New York, NY, May 2010
321. Member, Royal and Ancient Society of American Plastic Surgeons, Pebble Beach, CA, May 2010
322. Guest Faculty, International Symposium on Breast Beauty through Science, Stockholm, Sweden, June 2010
323. Faculty, Internal Society of Aesthetic Plastic Surgery Annual Meeting, San Francisco, CA, August 2010
324. Faculty, American Society of Plastic Surgery, Breast Surgery & Body Contouring Breast Symposium, Santa Fe, NM, August 2010
325. Keynote Speaker, International Society of Breast Surgeons, Annual Meeting, Mexico City, Mexico, September 2010
326. Faculty, American Society of Plastic Surgery Meeting, Toronto, Ontario, October 2010
327. Faculty, LifeCell Breast Augmentation and Reconstruction, Toronto, Ontario, October 2010
328. Faculty, The First Global Fat Applied Research Association, Dallas, TX, October 2010
329. Faculty, LifeCell BPS Bioskills Lab, Las Vegas, NV, November 2010
330. Faculty, American Society of Aesthetic Plastic Surgeons Baker Gordon Educational Symposium, Miami, FL February 2011
331. Faculty, LifeCell Surgical Solutions Symposium, Miami, FL, April 2011

Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process
332. Faculty, The American Society of Breast Surgeons Annual Meeting, Washington, DC, April 2011

333. Faculty, Southeastern Society of Plastic and Reconstructive Surgeons, Naples, FL, June 2011


335. Chairman, Allergan Academy APEX Surgeon Education and Training Program, Chicago, IL, July 2011

336. Faculty, American Society of Plastic Surgeons Breast Surgery and Body Contouring Symposium, Santa Fe, NM, August 2011

337. Chairman, Allergan Academy Scientific Program, Denver, CO, September 2011

338. Faculty, American Society of Plastic Surgeons Plastic Surgery Meeting, Denver, CO, September 2011

339. Faculty, LifeCell Surgical Solutions Symposium, Phoenix, AZ, October 2011

340. Chairman, Allergan Academy at the Cutting Edge, New York, NY, December 2011

**PAPERS PRESENTED AT NATIONAL MEETINGS:**
(Excluding invited presentations)


Manuscripts:


Movies:

Videos:


**BIBLIOGRAPHY:**


**PATENTS ISSUED (9-U.S.):**

U.S. Patent 5,092,348; issued March 1992
Title: Textured Tissue Expander
Inventor: G. Patrick Maxwell, M.D.

U.S. Patent 5,480,430; issued January, 1996
Title: Shape Retaining Fluid-Filled Prosthesis
Inventors: Dan Carlisle and G. Patrick Maxwell


Gel-Filled Implants. US. #5,282,857: February 1, 1994

Textured Surface Prosthetic Device. U.S. #5,344,388: September 6, 1994

Medical Prosthesis Containing a Gel-Filler Comprising Principally Water and Cellulose Derivative. U.S. #5,531,786: July 2, 1996.


Title: Variable Cohesive Gel Form-Stable Breast Implant
Inventors: G. Patrick Maxwell, M.D., Thomas E. Powell, Daniel A Carlisle
#WO 2007050693; issued May 3, 2007

Title: System and Method of Computer-Assisted Implant Selection for Breast Augmentation.
Inventors: G. Patrick Maxwell, M.D., Constantin Stan, M.D. Peter Damoc


PATENTS ISSUED/Filed-FOREIGN:


PATENTS PENDING (9-FOREIGN):


Skin Protector for Ultrasonic-Assisted Liposuction and Accessories. European Application (designating Germany, the United Kingdom, France, Italy, Netherlands, Belgium, Sweden, Switzerland, and Liechtenstein, Austria, Spain, Portugal and Denmark) No. 97,100,2852: Filed January 9, 1997.


Addendum B

Executive Summary
Tamarin Lindenberg, CEO, Healthcare in Transition, LLC

Master level professional with 20 years in executive management and behavioral research in healthcare, biotechnology and professional service industry; extensive track record in market and behavioral research and analysis, accelerated/focused growth, realignment, and innovative market positioning -- startups to global. Developer of cultural due diligence process for hospital acquisitions, patient advocacy and messaging platforms, and physician level reporting systems. Awarded Fellowship at Case Western Reserve University for Doctorate in Management. Highly regarded as a results oriented leader with strong interpersonal skills, and the ability to create, evaluate, analyze, and implement defined plans and objectives to achieve organizational goals. Recognized for ability to engage significant stakeholders in key initiatives. Expertise includes full range of business life cycles.

Significant Contributions
Developed strategic plans for startups in biotech industry, which included successful collaboration with mature biotech markets.

Created initial PI educational documents for first-time investigators; gained significant buy in for clinical research in immature market.

Evaluated existing structure for bringing diagnostic tests to market; designed strategies and teams to decrease time to market. Successfully engaged early investors.

Designed and led national QOL study in BRCA and Breast Cancer population resulting in recognition and support from global healthcare players. First study to evaluate impact of visual satisfaction in breast reconstruction on the healing process and resulted in multi-industry support for women’s health initiatives.

Engaged significant Advisory Boards in multiple corporations to leverage cross sector expertise and contacts to launch new initiatives. Resulted in extensive global network with repetitive success in various ventures.

Developed and instituted patient advocacy program for women facing reproductive and breast cancer resulting in increased media interest. Raised support for various initiatives for women facing reproductive and breast cancer through cause marketing strategies and innovations.

Participated in multiple NIH forums to evaluate clinical research in medically underserved populations; instituted strategies in local markets to better serve these populations.

Breast Reconstruction: The Vital Role of Self Perceived Beauty in the Healing Process
Established unique interface between clinical and behavioral research modalities which linked immature and highly evolved biotech markets.

Created key behavioral research program to identify barriers to healthcare access in African American Males (prostate cancer focus) which gained significant financial support in nonprofit arena.

Created training and development programs resulting in qualified local workforce in limited local market—IRB submission through clinical trial management.

Established cross-collaborative relationships between academic and private practice physicians, clinical and behavioral research methods, and emerging and mature markets.

Built industry collaboration among top leaders in distribution, biotech, professional service, healthcare, and retail services to increase bench strength for local economic development efforts.

Implemented financial tools and metrics for biotech support services, research institution, and private medical practices; P&L responsibility, cost containment, service mix evaluation, negotiation of key contracts, development of compensation plans, etc.

Led clinical research organization servicing the pharmaceutical industry in clinical trial research, and the community through behavioral research programs; created cross-collaborative opportunities for academia and private practice physicians.

Created and executed cultural due diligence system for multi-state hospital acquisitions resulting in successful rollup.

Designed and executed physician level insight reporting system resulting in increased share of highly competitive market.

Instrumental in delivering strategic insights in bidding process resulting in successful multi-state hospital acquisitions.

Create robust framework for human capital development, cross sector, to support economic development in secondary markets. Resulted in large scale interface between top industries, educational institutions, local government and key level talent.

Instituted business processes, financial modeling, pricing for services, and built organization’s infrastructure for biotech support services firm; tripled revenues in three years.

Developed virtual delivery system to allow utilization of top research professionals nationwide resulting in triple revenue increase in two years.

Developed and implemented SOPs for daily operations for client companies in healthcare, research, and biotech environments.
Led struggling client organization through change in partnership and loss of business; significantly improved cash flow resulting in 150% increase in reserve, restructured debt load providing cash flow relief, improved collection system resulting in 30% monthly increase, implementing billing requirements resulting in monthly increase of 60%.

Worked with senior management team of international multi-billion dollar company to realign regional departments which resulted in improved efficiency, increased performance, accountability, fostered teamwork and opened communications between, and within, four global regions of the company.

Examined existing staff resources, infrastructure and business needs for large scale Corporate Giving program for multi-billion dollar organization; provided a strategic framework that identified key positions, along with qualifications, role expansion, reporting structure, compensation levels, and improved delivery models for services.

Assisted marketing department in the process of identifying current market conditions, forecasting future growth and providing consistent delivery of services across business lines and regions; instrumental in analyzing delivery of services for integrated marketing platforms, creative development, public relations, and ROI tracking.

Led organization from a loss to a 200% increase in profit in 18 months by restructuring workforce, developing minimum production requirements, reducing overhead, and implementing revenue-generating strategies. In addition to increase in profits, key stakeholders salaries increased 40%.

Worked closely with external accountants, attorneys, and bankers in developing workout plans to ensure client organization’s viability during transitional period.

Strategically reorganized and relocated firm in a declining economic climate. Efforts in repositioning firm led to increased revenues of 25% and increased profits of 150% in highly competitive marketplace.

Successfully mentored new firm leadership through the development of a strategic plan designed to stabilize firm and increase its business base. Developed action plan with measurable results to ensure success of organization’s goals. Business revenues grew 20% in 6 months.

Led clients in presenting strategies and action plans, delivering to a public audience, speaking to media, or for a community cause, as well as in using audiovisual technology, and speaking from prepared materials or extemporaneously; resulted in the delivery of a message in reflecting sincerity, command of the subject, and dedication to the cause or outcome.

Facilitated leadership development programs for appointed client company executives and upper level managers, resulting in increased efficiency and greater profitability.
The above recognizes only a condensed version of accomplishments.

Community and Industry Involvement
Member (or past member) of Biotechnology Industry Council, Drug Association of America, Society for Clinical Research Professionals, Women Business Leaders in Healthcare, The Boston Regional Chamber of Commerce, The Memphis Regional Chamber of Commerce, The Boston Club, and Boston University’s Advisory Board for EMBA students; Mentor for women advancing in management roles in Fortune 500 companies through WUI in NYC.

Speaker at various industry conferences on topics of leadership, strategic planning, and large-scale realignment processes; author of various white papers on the business of biotechnology, medical research, leadership in transitioning organizations, large-scale realignment, top talent recruitment and retention, economic diversification in evolving metro areas, and employee relations.

Education
Case Western Reserve University, Cleveland, Ohio, Candidate for Executive Doctorate in Management with a concentration in Globalism; currently on hold

Cambridge College, Cambridge, MA; Master of Management (GPA 4.0), concentration in Organization Development

Continued education in mediation and complex negotiations to result in Court Mediator Certification

Northeastern University, Boston, MA; undergraduate work in Finance and Accounting (GPA 3.8)

Publications/White Papers
Economic Diversification in Evolving Markets; served as an educational resource for city and industry leadership in Memphis, TN


Memphis Woman Magazine, November 2001: “A Woman’s Influence in Family Health.”


“The Business of Biotechnology,” October 2001—served as an educational resource for emerging Principal Investigators in clinical research.
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