

Patient Education and Decision Making in Breast Reconstruction

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ABSTRACT

A well-informed patient who actively participates in decision making is an essential ingredient of successful outcome in breast reconstruction. The plastic surgeon must be prepared to answer all the patient's questions in a clear and concise manner. All women considering breast reconstruction need to understand the rationale for reconstruction and have realistic expectations for what can be accomplished. They need to consider the optimal timing and the advantages and disadvantages of each technical option. The patient education process can be enhanced by the thoughtful inclusion of growing set of educational tools and decision aids. This article reviews each of these issues and suggests a way to organize and present the essential material in a way that has proven effective with women in our practice.

KEYWORDS: Breast reconstruction, patient decision-making aid, patient education

There has been an explosion of information concerning breast cancer treatment and breast reconstruction. As a result, newly diagnosed women immediately encounter a complicated set of treatment choices that includes a bewildering array of options regarding breast reconstruction. Then, they must make informed decisions in the midst of emotional turmoil caused by the sobering realization, "I am a cancer patient." The challenge of plastic surgeons interested in breast reconstruction is to guide patients through the decision-making process. To do this successfully, the surgeon must have a concise explanation of the rationale for breast reconstruction, the various surgical options, and the advantages and disadvantages of each one. In addition to educating the patient, there is a need to inform family and friends who support the patient. These people may not always be present during direct encounters with surgeon, but they are likely to influence the patient's decision and ideally should somehow be provided with

good information as well. Taking full advantage of modern educational aids may make the task easier.

In this article we will review the importance of having a well-informed patient. We will review what we consider the most significant issues in breast reconstruction that must be communicated with the patient. We suggest a format that we have found successful and may be easily adapted to other surgeon's practices. Finally, we will consider educational aids that might be useful in the process.

THE WELL-INFORMED PATIENT

Contemporary health care places greater emphasis on patient education and patient involvement in medical decision making.¹⁻⁵ Beneficial effects of informing patients and inviting them to participate in the choice of treatment have been suggested, for example, with regard to patient compliance,⁶ patient satisfaction,^{7,8} clinical

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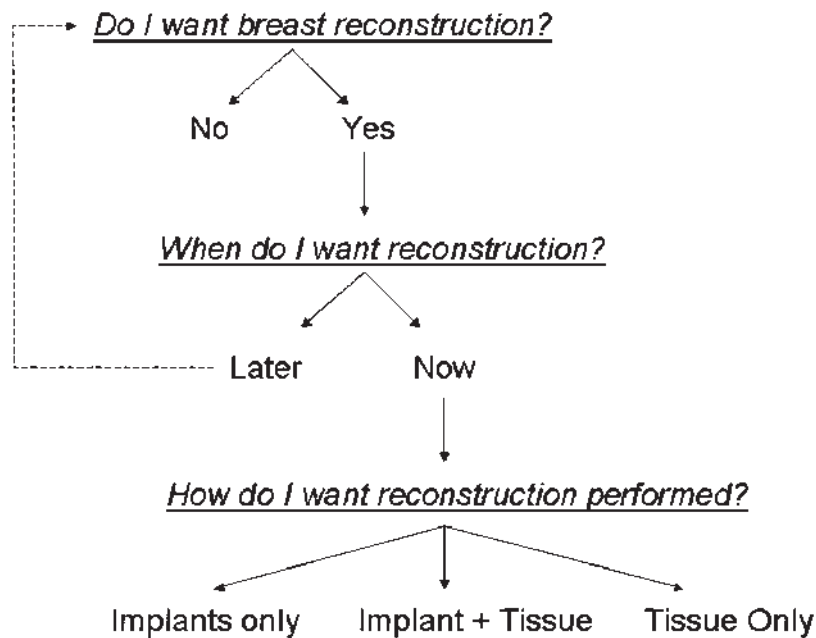


Figure 1 The basic decision tree for breast reconstruction candidates consists of three essential questions. A decision to have delayed reconstruction begins the process over again.

outcomes,^{9,10} and quality of life.¹¹⁻¹³ This is especially true regarding breast reconstruction where the outcome is heavily dependent on subjective factors and patient motivation. It is essential to fully inform the patient about all the options. A well-informed patient is more likely to have realistic expectations and be satisfied with the final outcome. The plastic surgeon must not only provide fundamental technical information about the surgery (e.g., methods, possible complications, additional procedures, etc.) but also assist the patient in clarifying her personal goals and priorities. This latter aspect of communication with the patient is often the most challenging and important.

Women often consider a wide variety of issues when coming to a decision. "Why should I consider reconstruction?" "Do I want a 'perfect' breast or just to avoid an external prosthesis?" "Can I afford the time to complete the process?" These are fundamental questions related to the procedure. Most women have additional concerns. "Who will manage my business?" "How will it affect my golf swing?" "How can I manage to not lift my 2-year-old for 1 month?" "Who will take care of the horses?" The relative weight assigned to these kinds of concerns determines whether breast reconstruction makes sense, when it should be performed, and what method might be indicated. Skillfully working with the patient to sort out these issues helps to ensure a successful outcome.

ESSENTIAL INFORMATION

It is not practical to exhaustively cover all the issues relevant to breast reconstruction with the patient. Never-

theless, there is specific essential information that all patients need. When explaining breast reconstruction to the patient, it is useful to organize the options in the form of a decision tree (Fig. 1) and assist the patient through each step. There are three essential questions the patient must ask: (1) Do I want breast reconstruction? (2) When do I want it? (3) How do I want it to be performed? In addition, there are several other commonly asked questions that the surgeon should be prepared to answer.

"Do I Want Breast Reconstruction?"

This is the most basic and important question. Research shows women choose to have reconstruction for a variety of reasons. The benefit to psychosocial health is perhaps the prime incentive. In the past, many believed that delayed reconstruction was better because patients would be more appreciative if forced to live for some time with a flat chest wall. This concept is now considered unacceptable, and many women regard this attitude as evidence of a lack of concern for the psychological impact of mastectomy.¹⁴ Women who undergo immediate reconstruction tend to accept the new breast as an integrated part of their body¹⁵ and demonstrate reduced psychosocial morbidity.¹⁶ They have significantly less "distress" in recalling the surgery,¹⁷ are less likely to be "repulsed" by their own naked appearance, and have more freedom to dress than women who do not have reconstruction.^{18,19} It is difficult to demonstrate a difference in psychological impact between the various reconstructive techniques,²⁰ but it is reasonable to expect patients to score higher if the reconstructed breast is a true

representation of the appearance and texture of their natural breast. When compared with breast conservation (i.e., "lumpectomy" and radiation), mastectomy with immediate reconstruction yields similar psychosocial outcomes. There is no measurable difference in overall psychosocial adjustment to illness or satisfaction with relationships or sexual life, but there is a specific advantage of breast conservation over breast reconstruction in terms of maintaining pleasure and frequency of breast caressing during sexual activity.²¹ Body image can be adversely affected by the additional scarring associated with reconstructive surgery, but the overall psychological morbidity appears to be the same as with breast preservation.²² Thus, breast reconstruction offers psychological benefits, and it appears to compare favorably to breast conservation therapy in terms of psychosocial outcome. As the surgeon interacts with the patient, it is helpful to listen for clues or specifically inquire about the patient's attitudes in these areas to determine whether they will experience a benefit from reconstruction.

Some factors that influence the decision to have reconstruction are obvious: breast size, overall health, body image, and social situations. There are other important issues that bear upon the patient's decision but that may be easily overlooked in preoperative discussions. First, it is important to put reconstructive surgery into proper context with the overall cancer treatment plan. Reconstructive surgery should be considered as an integral part of breast cancer treatment. Other members of the oncology team must be aware of plans for reconstruction to ensure that the patient's condition is comprehensively evaluated and appropriately managed. Although reconstructive surgery is secondary to other treatments that are directly related to survival, it is an essential part of recovery and return to normal living for many women. It should not be considered frivolous or a matter of vanity. Second, any women considering breast reconstruction must understand that choosing it is more than simply electing to have surgical procedure. It typically involves more than one surgical procedure. There may be frequent clinic visits. Complications may occur that require treatment or unplanned procedures. Final results often require many months to realize, depending on the technique of reconstruction. One of the most important factors for successful decision making is to determine the patient's degree of willingness to engage in this process. The patient must understand and be committed to this.

Choosing not to have breast reconstruction is, of course, a very satisfactory option for some women. Some may prefer to avoid further surgery. Others wish to minimize the possibility of inconvenience associated with treating complications. In these women, it is best to defer reconstruction and perhaps choose to use an external prosthesis to enhance personal appearance. This is certainly the best option for any woman who simply

cannot make a decision regarding reconstruction or maintains unrealistic expectations about the outcome.

"When Do I Want Reconstruction?"

After deciding to have breast reconstruction, the next decision is to choose the timing. Each woman needs to understand the rationale for choosing to have reconstruction performed at the same time as the mastectomy or later after recovery from surgery and completion of any associated treatments. The best candidates for immediate reconstruction are women in general good health with early-stage disease based on the size and location of the tumor. Immediate reconstruction for more advanced stage II or III disease is controversial and should not be routinely offered at this time.²³ There are occasional exceptions such as reconstructive surgery for chest wall coverage after an extensive resection for advanced disease. Under these circumstances, breast reconstruction is accomplished incidental to achieving chest wall coverage.

There are several important aspects of immediate reconstruction that the patient must understand. For most women it yields more natural-appearing results compared with delayed reconstruction. The tissues that remain immediately after the mastectomy are unaffected by soft tissue contraction and scarring. The inframammary fold and other important landmarks that determine unique shape of each woman's breast are better preserved. These features enhance the outcome for all techniques of reconstruction, but they are especially important when using tissue flaps. Skin from the flap can be used to patch areas of breast skin that have been removed with the mastectomy. The retained portions of the breast skin envelope tend to return to a natural shape when breast volume is restored. As a result, the reconstructed breast can assume the shape that more closely resembles the patient's native breast. The aesthetic task of the reconstructive surgeon is simplified.

Many women have heard of skin-sparing techniques and often will ask about how it relates to reconstructive surgery and cancer safety. Skin-sparing mastectomy technique is oncologically safe, and it essential to maximize the aesthetic result.^{24,25} A skin-sparing mastectomy removes the nipple, the areola, and the scar from previous open biopsies. The site of a needle biopsy does not require excision. All remaining portions of the skin envelope are preserved. In patients with large breasts and excessive skin, the mastectomy may be performed through a Wise-pattern incision, allowing a controlled reduction of skin envelope to yield the most natural result. Performing a mastectomy in this way requires skill from the ablative breast surgeon. It is more difficult and time-consuming than a conventional mastectomy, but the aesthetic outcome of the reconstruction is significantly affected by precision in the

design of incisions and technique of skin flap elevation used for the mastectomy. For this reason, it is imperative that the plastic surgeon work in a cooperative way with the ablative surgery team and that the ablative surgeons be committed to achieving good esthetic results.

It is important that the patient understand how radiation therapy affects the timing of reconstruction. When radiation is not anticipated, immediate reconstruction is the preferred option. When radiation therapy is required, it may be preferable to have delayed reconstruction after completing radiation treatments.^{26,27} In patients who still prefer to have an immediate reconstruction it may be advisable to reconstruct the breast with a larger volume to offset postradiation tissue atrophy and fibrosis. In some patients, the need for radiotherapy is uncertain until the status of the axillary lymph nodes can be determined after the mastectomy and axillary dissection or sampling. Under these circumstances, the patient might consider a "delayed-immediate" reconstruction method, pioneered by Kronowitz,²⁸ in which a tissue expander is temporarily placed beneath the mastectomy flaps and filled to the appropriate volume needed to preserve the skin dimensions. If the lymph nodes are free of disease and the patient is not a candidate for radiation, the expander is removed and an autologous breast reconstruction is performed. If radiotherapy is needed, the expander is removed and reconstruction is performed after the completion of the radiotherapy. In this way the natural envelope of the breast is preserved during the radiation therapy.

"How Do I Want Reconstructive Surgery Performed?"

Once the patient chooses to have reconstruction, she must select a technique that is most likely to help her meet her goals. From a patient's point of view, there are essentially three types of options: (1) tissue expansion followed by breast implant placement, (2) combined tissue flaps with breast implants, and (3) autologous tissue flaps only. Each approach should be explained to the patient. Within each category there are specific technical variations, but it may not be necessary to describe each of these in detail and risk confusing the patient. After interviewing and examining the patient, the surgeon then should describe those methods for which the patient is considered a suitable candidate. The patient should then be encouraged to choose based on her goals and an understanding of the advantages and disadvantages of each technique.

The first method to consider is reconstruction based on the use of tissue expanders and breast implants alone. From the patient's viewpoint, the advantages of this technique are that it involves minimum additional surgery when performed at the time of the mastectomy,

has a recovery period essentially the same of that of the mastectomy alone, creates no additional scarring, and poses the least operative risk. This method is ideal for a slender, small-breasted woman with minimal ptosis who wishes to avoid additional scarring and time for convalescence. The disadvantages of this technique are the length of time necessary to complete the entire reconstruction (up to 1 year), the requirement for a minimum of two operative procedures, and a less predictable cosmetic result. Breast implants may develop late complications such as capsular contracture, infection, extrusion, or deflation. There is a limited potential to control the final shape of the breast using this technique. Because of this, surgery may be necessary to the opposite breast to achieve symmetry. It may also be suitable for women undergoing bilateral reconstruction because symmetry is more easily achieved if both breasts are restored using the same technique. Women who elect this type of reconstruction must understand that breast implants do not have an unlimited service life and that additional surgery will be likely be required to replace the breast implant at some time in the future. The patient must be comfortable with the idea of having a breast implant. If a silicone gel-filled device is used, then it is imperative to be certain that the patient understands the nature of the controversy surrounding these implants and is comfortable with the fact that there remain unresolved questions about them that prevent general release to the market by the Food and Drug Administration. Patients who receive radiotherapy are poor candidates for breast reconstruction using implants alone due to the incidence of soft tissue contracture and wound-healing difficulties. Reviewing these points with the patient provides a sound basis for assessing this option.

The next group of procedures to describe to the patient is reconstruction using a combination of a tissue flap and a breast implant. The tissue transfer provides the necessary soft tissue coverage to restore the breast without the need for tissue expansion. The flap may contribute to volume replacement, depending on the amount of soft tissue available with the flap selected, but the majority of the volume depends upon a breast implant. The latissimus dorsi musculocutaneous flap is the most common tissue transfer used in combination with breast implants, although other flaps may also be used depending patient preference and tissue availability.²⁹ The principal advantage in using a tissue flap is immediate replacement of missing skin and soft tissue. The advantages of this technique are that the implant is protected by abundant tissue, a period of tissue expansion is avoided, and the full benefit of preserving the breast skin is realized to achieve a natural-appearing breast. The disadvantage of this technique compared with implants alone is that it results in additional scarring and requires a longer period of recovery. For many

patients, this approach represents an acceptable compromise between implant-only reconstruction and more elaborate autologous tissue reconstruction, incorporating some of the advantages and disadvantages of each technique.

The final group of procedures to present to the patient consists of those based on using only autologous tissue. These are the most technical methods of breast reconstruction, but consistently yield the most durable, natural-appearing results.³⁰ There are several possible donor sites for autologous tissue reconstruction, and a patient may present to the surgeon having read about them from published sources or on the Internet. Some women request a specific type of flap for reconstruction such as a deep inferior epigastric artery perforator (DIEP) flap or a superior gluteal artery perforator (S-GAP) flap. In our view, it is best to agree preoperatively only to the tissue donor site to be used for the reconstruction and avoid committing to a specific technique of tissue transfer. If the patient chooses to use the lower abdominal skin and subcutaneous fat as a tissue source, it may be explained that the surgery will be designed to transfer the tissue to the area of the breast defect using whatever means appears to be the most reliable during the time of surgery. We proceed stepwise through a menu of choices, selecting the one that appears to allow transfer of the appropriate amount of tissue with the greatest chance of avoiding complications. The first method to consider is the superficial epigastric artery perforator (SIEP) flap. If this does not appear advisable, then the DIEP flap is explored and considered. If this appears unsuitable, then a transverse rectus abdominis myocutaneous (TRAM) flap is harvested for microvascular transfer using muscle-sparing or full-width inclusion of the rectus muscle. If a free TRAM does not appear reliable due to factors such as inadequate recipient vessels on the chest, then a conventional pedicled TRAM is considered. Finally, if a conventional flap appears to have inadequate blood supply, then a delay procedure is performed and plans made to return to the operating room to perform the tissue transfer and complete the breast reconstruction sometime in the following 3 weeks. If a delay procedure is performed, the dimensions of the mastectomy skin flaps must be preserved with minimal deformation by contraction and scarring. Temporarily inserting fully inflated tissue expanders accomplishes this. The mastectomy skin flaps provide adequate coverage over the expander for 14 to 21 days. In many women the microvascular technique is preferred because there is less risk of partial flap loss or localized areas of fat necrosis due to a more reliable blood supply. The advantages of autologous tissue reconstruction are complete restoration of the breast mound in a single stage in most patients, avoidance of potential problems associated with breast implants, and predictably good cosmetic results.^{31,32} The disadvantages are the

magnitude of the operation, additional scarring, risks of complications (e.g., abdominal bulging), and a longer period of convalescence. This is the best operation for patients for whom the goal is to achieve the most natural breast restoration possible and who are less concerned about the amount of surgery, scarring, and recovery period.

“Now That That Is Settled, What About. . .?”

Related to the three fundamental questions covered above, it is important to also be prepared to respond to closely related questions that patients commonly ask. These relate to surgery to the opposite breast, bilateral breast reconstruction, and reconstructive options for partial mastectomy defects after breast conservation.

Achieving breast symmetry is an important goal of breast reconstruction for most women. This is often difficult to achieve following unilateral breast reconstruction. As a result, the patient is faced with decisions regarding potential surgical procedures on the healthy breast. For shape asymmetry without significant volume discrepancy, the appearance of the breast may be satisfactory in clothing that supports the opposite breast. Small discrepancies in volume may be masked in clothing by insertion of extra padding into the brassiere. For greater amounts of asymmetry or in women with higher standards for a natural appearance without clothing, surgery will be required on the opposite breast. This can involve augmentation, reduction, mastopexy, or a combination of these procedures depending on the nature of the deformity and willingness of the patient to accept scars on the normal breast. The timing of these procedures is important. Sometimes it is difficult to predict with certainty the final shape and volume of the reconstructed breast. Even if possible, some patients still find it difficult to visualize the final appearance and are undecided about whether to have immediate surgery on the contralateral breast. For these reasons, it is our preference in most cases to encourage the patient to wait until the final shape of the reconstructed breast is known before committing to alterations on the opposite side.

Another question frequently asked by patients is whether to perform a prophylactic mastectomy on the unaffected breast to perform bilateral reconstruction. Patients considering autologous reconstruction are more likely to wonder about this because the TRAM flap is only available once. It is our view that prophylactic mastectomy is a decision that should be based upon the risk of developing breast cancer in the opposite breast. This risk is related principally to the histological type of tumor and other indicators of malignancy such as nuclear grade, the presence of specific tumor markers, and so on. Also important is the genotype of the patient. It is best in most cases to defer this discussion to the ablative surgeon. We discourage women from having

prophylactic mastectomy simply to achieve a symmetric reconstruction or to avoid "worrying" about the possibility of cancer recurrence. The reconstructed breast still is only a simulation of real anatomy regardless of how natural it may appear. Women who have prophylactic mastectomy to lower concerns about recurrence often are disappointed when they discover after surgery that the specter of tumor recurrence is ever present and still a source of anxiety for the future despite a prophylactic procedure.

Finally, some patients wonder about the possibility of reconstructive surgery after breast conservation if partial mastectomy and radiotherapy yield disappointing aesthetic results. Because of the irradiated tissues, repair of partial mastectomy defects usually require addition of tissue.³³ The latissimus dorsi musculocutaneous flap is a useful option. We discourage using a TRAM flap for this purpose, because it is the best option for future breast reconstruction if it is necessary. If there is insufficient volume provided by the flap alone, then a breast implant can be used in addition as long as it is used in conjunction with the flap. Often a procedure will be required to the opposite breast to achieve symmetry.

PATIENT EDUCATION AIDS

The traditional way to deliver information to the patient is during a face-to-face encounter. Although these meetings are mandatory and form the essential foundation for the patient-physician relationship, they are not necessarily the most efficient and reliable way to impart information. Clinic visits to discuss breast reconstruction often occur when the patient has already may have spent a long day at the clinical laboratory providing specimens, undergoing diagnostic procedures (e.g., imaging, needle biopsy, etc.), or meeting with other physicians and thus being exposed to a large amount of information not directly related to reconstructive surgery. By the time they actually are able to meet with the plastic surgeon they are already tired and overwhelmed. In training institutions, there is the additional factor of other providers being present in the room such as trainees. It may be difficult under these circumstances for the patient to listen and concentrate on what is being told. For these reasons, it is helpful to consider use of educational and decision-making aids to facilitate the process of fully informing the patient and enabling her to make the best decisions.

When more than one treatment is available for a medical condition, patient decision aids are designed to provide understandable information and highlight the important factors to consider when coming to a decision. They improve knowledge, reduce decisional conflict, and stimulate patients to be more active in decision making without increasing their anxiety.³⁴ Several decision aids have been developed related to breast cancer including

decision boards^{35,36} and various media formats including audiotape/booklet combinations,³⁷ interactive computer programs,^{12,38} and counseling/video programs.³⁹

Soon after first being presented with the diagnosis of breast cancer a woman will begin a process of gathering information. They may recall knowledge about the disease acquired from personal experience with family members or friends who had the disease. Published written material (e.g., books, pamphlets, etc.) may be the next source of information consulted. These are often available from health care organizations or bookstores. The Internet plays an increasing role in providing information, and it has become a powerful tool to disseminate information on virtually any health concern. One advantage of Web-based information is that it tends not to become outdated due to the ease with which it can be updated. Despite this, information found on the World Wide Web is not necessarily reliable, because it usually is not peer-reviewed or objectively edited. Therefore, it must be accepted with caution.⁴⁰

Interactive digital media are gaining the rapid popularity and have proven beneficial in medicine. For example, interactive software programs designed to assist diabetic patients have been well accepted and easy to use. They improve knowledge, motivation, and self-care behavior.^{41,42} Interactive software used to educate patients with congestive heart failure also showed positive results regarding patient acceptance and effective information acquisition in reduced time when the patient could learn independently on their own time.⁴³ The software designers emphasize, however, that interactive programs should only augment and not replace traditional patient education programs.⁴⁴

Despite the apparent benefits regarding new tools that empower the patient to be more responsible for decision making, questions exist about the ultimate value of this approach to patient care. Some wonder to what extent patients are indeed interested in being involved in treatment decisions.³⁴ Decision aids can provide too much information, leading to confusion and actually increase distress. Moreover, when the treatment chosen by the patient ultimately proves unsuccessful there might be feelings of regret and self-blame.⁴⁵ For this reason, some patients simply prefer to have someone else make decisions for them. Physicians may not be reluctant to delegate decision responsibility to the patient because of concerns that it could lead to a loss of confidence in the physician and impair the doctor-patient relationship,⁴⁶ be too time-consuming,⁴⁷ or result in the patient electing to have more costly or potentially harmful interventions.⁴⁸ Despite these concerns, in breast reconstruction it seems advisable to include the patient as much as possible in the decision process.

In light of this, we designed an interactive software program as an educational tool for breast reconstruction. "Breast Reconstruction: What You Need to

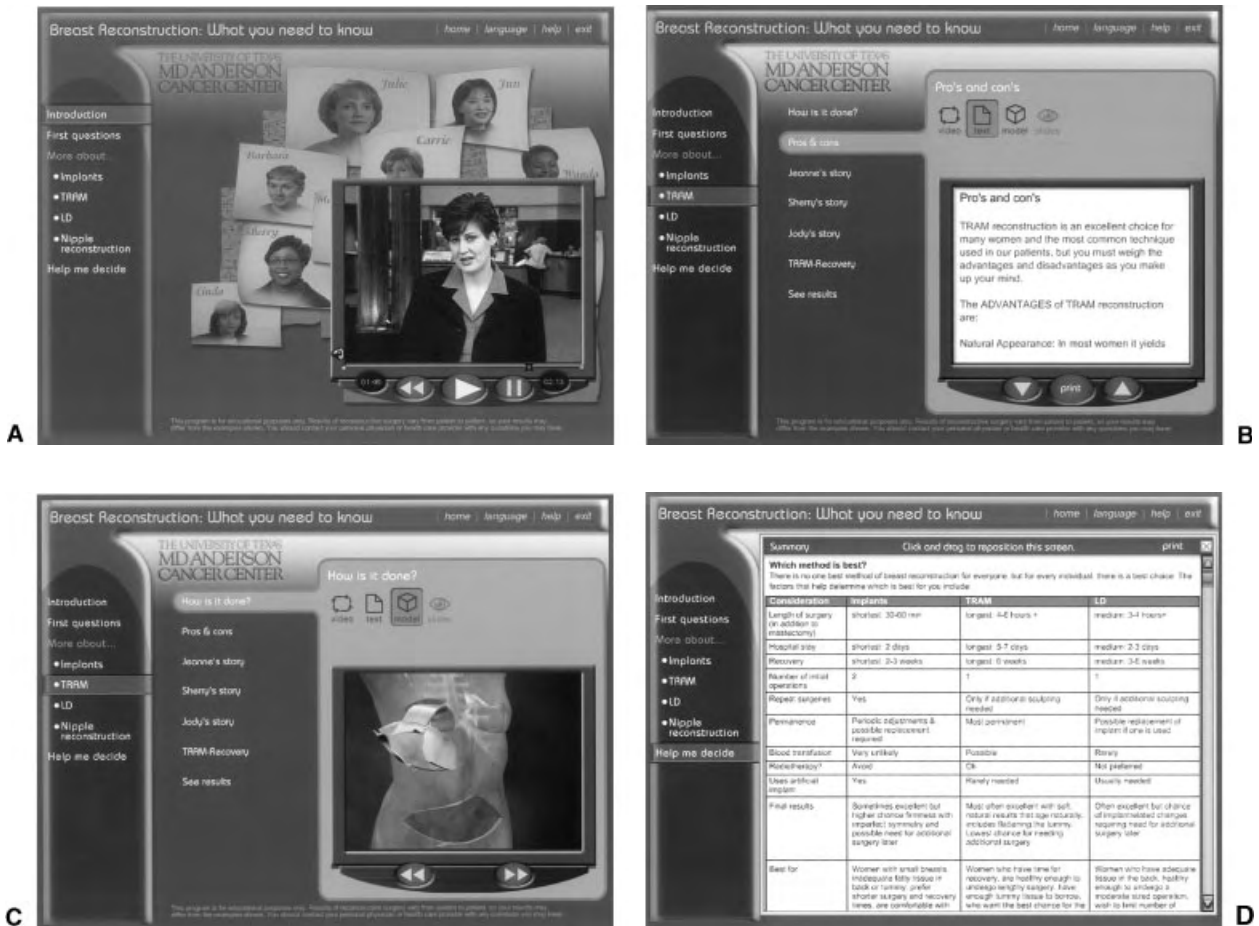


Figure 2 User interface for “Breast Reconstruction: What You Need to Know.” Information is provided in an interactive format using either (A) short videos or (B) text depending on patient preference. It includes (C) three-dimensional animations of techniques and (D) table summaries to aid in decision making.

Know” is an interactive software program that includes high-quality three-dimensional animated graphics, patient testimonials, photographs of results, and video explanations from plastic surgeons as well as specialists in surgical, medical, and radiation oncology (Fig. 2). The content was selected based on patient focus groups and faculty discussions at the University of Texas M. D. Anderson Cancer Center. It is organized to answer general questions about breast reconstruction and provide detailed explanations of the various techniques. The advantages and disadvantages of each method are presented in a balanced way, including why a woman may choose to have no reconstruction. There are stories from women who explain why they chose a particular method and how it has affected their lives. The user interface is intuitive and simple. It is designed to run on any computer. All information is printable. One CD-ROM contains both English and Spanish language versions. This product took 3 years to complete. We have been using it in our practice for nearly 2 years. We make it available for patients to view in our clinic or at home. We have found it effective for helping women make in-

formed choices and to reduce the time required for preoperative consultations. Currently, we are conducting a randomized controlled study to document its effectiveness as an educational tool. Preliminary results from this ongoing study suggest that patients who use the software score higher in knowledge of breast reconstruction and have greater understanding of the reconstructive options compared with women who had presented material through only conventional means (i.e., printed material, direct physician instruction). Data regarding the influence of the educational material on patient anxiety and outcome satisfaction is still being gathered.

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