IMPORTANCE OF DECISION QUALITY IN BREAST CANCER CARE

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Abstract

Background: In breast cancer, treatment decisions are challenging as patients, their families and providers need to sort through an ever expanding array of options for surgery, radiation, reconstruction and systemic therapy.

Objective: To describe efficacy and effectiveness of interventions designed to improve decision quality in breast cancer care.

Methods: We describe the competencies required of providers and patients to engage in shared decision making, and then present interventions and metrics that have been shown to improve the quality of medical treatment decisions. A case study illustrates how decision support tools have been implemented in a cancer center in the United States.

Results: Patients and providers face multiple decisions after a breast cancer diagnosis and too often these decisions are made without patients having adequate information or involvement. Decision aids, prompt sheets and consultation recordings have been shown to improve the quality of decisions by increasing knowledge, reducing decision conflict and improving communication. These tools have been successfully integrated in a variety of cancer centers, but require some resources and infrastructure to make it work.

Conclusions: Patients, their families and providers need to work together to select cancer treatments. These interactions are complex and can be improved through the implementation of decision support.

Resumen

Antecedentes: En cáncer de mama, las decisiones de tratamiento son difíciles ya que los pacientes, sus familias y los proveedores necesitan elegir entre una gama cada vez mayor de opciones de cirugía, radioterapia, reconstrucción y terapia sistémica.

Objetivo: Describir la eficacia y la efectividad de las intervenciones diseñadas para mejorar la calidad de la decisión en el tratamiento del cáncer de mama.

Métodos: Se describen las competencias requeridas de los proveedores y los pacientes para comprometerse en la toma de decisiones compartida. A continuación presentamos las intervenciones e instrumentos que han demostrado mejorar la calidad de las decisiones de los tratamientos médicos. Un estudio de caso ilustra cómo las herramientas de apoyo a las decisiones se han llevado a cabo en un centro oncológico en los Estados Unidos.

Resultados: Los pacientes y los proveedores se enfrentan a múltiples decisiones después de un diagnóstico de cáncer de mama y con demasiada frecuencia estas decisiones se hacen sin que los pacientes tengan una adecuada información o participación. Las ayudas a la decisión, las hojas y los registros de la consulta se han demostrado que mejoran la calidad de las decisiones, al aumentar el conocimiento, reducir el conflicto decisional y mejorar la comunicación. Estas herramientas se han integrado con éxito en una variedad de centros oncológicos, pero para su adecuado funcionamiento requieren de determinados recursos e infraestructura.
Introduction

After a diagnosis of cancer, breast cancer patients have a dual burden. They need to come to terms with a life threatening diagnosis, and they need to make a decision about treatment. Most women with breast cancer face multiple treatment decisions, about surgery, reconstruction, and adjuvant therapy. Many patients struggle with the decision making period and report significant anxiety and distress during the time between diagnosis and treatment(1,2).

In the United States, studies have documented variation in treatment rates that suggests that whether a woman gets a lumpectomy or mastectomy may be more influenced by where she lives and which doctor she sees than by her preferences for keeping or losing her breast(3). In quality initiatives, variation is often seen as a problem that needs to be minimized or eliminated. Appropriateness criteria and quality measures have been set to minimize variation in rates of procedures. In breast cancer, rates of breast conserving surgery have been promoted as a quality criteria, with higher rates indicating higher quality care(4). However, the appropriate response to practice variation differs depending on the situation. When a procedure is known to provide significant benefits with little or no risk, decisions are straightforward. The goal is to minimize variation by delivering the treatment to all who are eligible.

But when effectiveness is uncertain, when the increase in benefit is marginal, or when the treatment has significant risks or side effects, the decisions are complex. In these situations, the right treatment cannot be determined by medical features, rather the right treatment is the one that best achieves an informed patient’s goals. Consensus statements and practice guidelines for many breast cancer treatment decisions now recognize the appropriateness of multiple options and the importance of incorporating patients’ preferences when selecting treatment(5, 6).

Consider the following three examples where patients and providers must make tradeoffs:

- Mastectomy or lumpectomy: patients must consider how they feel about keeping their breast, and whether it outweighs concerns about having radiation therapy, the small increased chance of ipsilateral recurrence, and the possibility of needed multiple excisions to get clear margins.
- Breast reconstruction or not: patients must consider how they feel about living without a breast, their desire for normal appearance in and out of clothes, the ease of dressing and daily activities with and without a prosthesis, and the chance of complications and recuperation associated with reconstructive surgery.
- Systemic therapy or not: patients with stage I disease have a good
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prognosis after local therapy, and must consider whether the small improvement in survival and reduction in recurrence is worth the side effects and chance of serious complications from these therapies.

How well do patients and providers make these kinds of treatment decisions? Several studies suggest that patients have significant gaps in knowledge. For example, in a large population based sample of early breast cancer patients, only half understood that survival was the same with either mastectomy or lumpectomy. In another study, patients believed that adjuvant chemotherapy would provide about an 80% reduction in their risk of recurrence, at least twice as much as it actually provides.

When patients are informed about the options and have realistic expectations about the benefits and harms, it changes their goals and their decisions. Peele et al (2005) randomized early stage breast cancer patients to view a decision aid that presented their absolute risk of recurrence and survival with and without chemotherapy. In the decision aid group, 57% chose to have chemotherapy compared to 87% of those in usual care. Providing treatment to a patient who would not have chosen it had they been informed, is problematic.

In surgery, there is a growing trend for using checklists to ensure that everything that should happen in the operating room does happen. Equally important is making sure that the right patient is in the operating room in the first place, and that the right operation is being done for that patient. The former is concerned with the execution of the decision, the latter is concerned with the quality of the decision making process. This paper describes the evidence base for decision support interventions aimed at improving decision quality, and presents an example of their implementation in a U.S. cancer center.

Shared decision making: competencies, interventions and metrics

In cancer care specifically, and medicine more generally, the last few decades have seen a shift away from paternalistic approach toward a more patient-centered approach to decision making. The increasing role of patients in decisions, however, has created its own set of problems. Patients facing cognitive and emotional overload may see responsibility for decision making as an added burden. A more collaborative approach to medical decision making, called shared decision making, recognizes the critical roles of both providers and patients and then need for shared responsibility.

There is a complex set of competencies required for doctors and patients to make high quality, shared decisions, and to implement those decisions effectively. Physicians must know the relevant clinical evidence, be able to interpret it accurately and apply it appropriately to the individual patient's situation. When there are gaps in the evidence, providers may need to gather outside expert opinion. Then, providers must translate the relevant clinical evidence in an understandable way to patients and family members. Providers must also have skills to elicit the patient's goals and concerns and appropriately assess which treatment would best achieve the patients' preferences. In some cases, the implementation of a treatment choice requires significant effort on the part of the patient, and providers need to monitor and assure sufficient patient motivation and self-efficacy to carry out the decision.

Patients also need many competencies to engage in shared decision making. Patients often need to adjust to the emotional impact of a new and threatening
diagnosis, or the debilitating impact of painful or bothersome symptoms in order to be able to absorb information and engage in discussions. Patients often need to recognize and be willing to readjust their sense of urgency—a common and unwarranted need to do something right away—when, in fact, there is ample time to learn about options and make a considered decision. Patients cannot simply show up and expect the provider to present the information and make a recommendation. Rather, patients need to prepare for the visit, and come ready to discuss their questions and concerns. During the visit they need to speak up if they do not understand, or if the provider is not accurately representing their goals and concerns. These competencies are especially challenging for patients with limited health literacy or numeracy and for a growing number of patients in Western countries, language barriers impede communications. Given the extensive set of tasks required to make complex decisions, it is not surprising that patients and providers do not always do it well.

Despite these challenges, it is important to pay attention to the quality of decisions. Poor communication of information about illness and treatment is one of the most frequent sources of patient dissatisfaction\(^{(16)}\). Studies have found that poor quality decisions can detract not only from patient satisfaction, but also from quality of life and health outcomes\(^{(17-21)}\). Good decisions, ones where care is tailored to informed patient preferences is have been associated with increased patient satisfaction, as well as improved quality of life and outcomes\(^{(22,23)}\). In breast cancer, studies suggest that whether the patient reported having a choice of surgical treatment had a bigger impact on psychological adjustment and body image that the treatment itself (whether someone had mastectomy or lumpectomy)\(^{(24-26)}\). Women who are involved with their treatment decisions are less likely to be anxious or depressed and tend to feel more confident and optimistic about the future\(^{(26-28)}\).

**Patient decision aids**

Many different tools, methods and approaches have been developed in an attempt to improve the quality of treatment choices. Some interventions are focused on physicians, such as training or education in one or more of the competencies described earlier. Other interventions focus on patients, such as information booklets or brochures, prompt sheets or lists of frequently asked questions to use during visits, and decision aids. Here, we briefly review the patient-focused interventions, with specific attention on patient decision aids.

Patient decisions aids (PtDAs) are educational materials that are designed to support patients in the decision making process. PtDAs provide information relevant for a specific clinical decision about a test or treatment, such as a description of the disease, the available options and the potential outcomes. Often PtDAs will provide probabilities of the different outcomes and the timing of those outcomes. PtDAs also provide values clarification, helping patients think through their goals and concerns to develop a treatment preference. The tools are available in a variety of media, print, audio/visual and Internet, and some including health coaching component.

The International Patient Decision Aids Standards group has generated consensus around a core set of twelve criteria for PtDAs. These twelve areas highlight the complexity of these tools, and place a strong emphasis not only on careful interpretation of the medical evidence, but also on balance (e.g. that the options are presented equally), conflict of interest (e.g. assurance that the developers do not have
a financial stake in one or more of the options presented), and other factors\(^{(29)}\).

The Cochrane Collaborative systematic review of decision aids now includes close to 60 randomized trials of these tools. In general, studies have found that PtDAs increase knowledge and realistic expectations, help patients who are undecided make a choice, and increase patients’ desire for participation, without increasing anxiety\(^{(30)}\). In a subset analysis for elective surgery procedures (e.g. herniated disc surgery or elective bypass surgery), PtDAs appear to reduce desire for surgery by about 20\%\(^{(30)}\). These tools have been evaluated extensively in the US, Canada, Australia and United Kingdom. Although it is likely that they will provide similar benefits in Spain, more research may be needed to adapt these tools for use in different countries and cultures\(^{(31)}\).

**Prompt sheets and recordings**

Some decision aids have worksheets or prompt sheets that help patients think through their questions for the doctor. Studies have found that simply prompting patients to make a list of questions, even without the educational component of a decision aid, can lead to improved interactions and outcomes\(^{(32-35)}\). The prompt sheets can be based on frequently asked questions, such as those identified by the National Cancer Institute in a review of cancer patient information needs\(^{(36)}\). Or, they can be organized according to conceptual models of decision making\(^{(37,38)}\). Some examples of prompt sheets are available online at [http://www.psych.usyd.edu.au/cemped/com_question_prompt.shtml](http://www.psych.usyd.edu.au/cemped/com_question_prompt.shtml); [http://www.guidesmith.org/questions-for-your-doctor/](http://www.guidesmith.org/questions-for-your-doctor/); and the Ottawa Personal Decision Guide, at [http://decisionaid.ohri.ca/decguide.html](http://decisionaid.ohri.ca/decguide.html).

Perhaps equally important for patients is to have a record of what happened during the visit. Many patient advocates recommend that patients bring a family member or friend to take notes, because they recognize the challenge of trying to remember all of the information presented by the doctor. Studies that have evaluated the impact of providing patients an audiorecording of the visit have shown that patients value these recordings, and that they may protect physicians from complaints and legal conflicts\(^{(36,39)}\). Even better than an audiorecording is a written summary in language that patients can understand (usually not satisfied by a copy of the dictated note). Having a written summary that can be reviewed and shared with family and friends is ideal, yet this practice is not a routine part of cancer care.

**Instruments to measure decision quality**

Seldom are organizational or behavioral changes made without reliable metrics and measures of quality. Perhaps there would be more widespread attention to these issues if there were better metrics. For example, if cancer centers knew that fewer than half of their early stage breast cancer patients understood that survival is the same with breast conserving therapy and mastectomy; or that their patients who felt strongly about avoiding radiation therapy were just as likely to have lumpectomy as mastectomy (indicating a lack of tailoring to patients’ preferences) –might that prompt concern over the quality of the decision making process?

To promote high decision quality, it is important to be able to measure how informed patients are and how often they get treatments that match their goals. For any decision, there is a core set of information that patients should understand before selecting treatment. For example, the following bullets highlight some of the key pieces of information that a patient should understand before making decisions about surgery for breast cancer:
• In general, patients who have breast conserving therapy live as long as those who have mastectomy.
• For most women, there are two reasonable ways to treat it—breast conserving therapy or mastectomy (with or without reconstruction).
• Women who have breast conserving therapy have a slightly higher chance of having cancer in the breast that they keep compared to women who have mastectomy.
• Most women who have breast conserving therapy are satisfied with the way their breast looks after treatment.
• About 10 to 50 out of 100 women who have breast conserving therapy will need to have more than one operation to remove the tumor completely.

This doesn’t represent all the information patients need to know but does cover some of the key issues that are relevant when trying to decide between the choices.

Once they understand this information, patients then need to take time to consider what the different possible options might be like for them, in their lives. Before the diagnosis, most women have little experience with cancer treatments, and do not know what it will be like to live without a breast, or to experience premature menopause due to chemotherapy. The patient who imagines incorrectly the quality-of-life impact of a future health state is likely to make a poor decision\(^{(40-42)}\). Also, preferences are only opinions, and opinions can be well informed or poorly informed, and they change over time\(^{(43)}\).

It is important for clinicians to be able to help patients think through their goals. Thus, for example, providers might ask: “How do you feel about keeping your breast?” “How important is it to avoid radiation therapy?” “How do you feel about removing your breast, will that give you peace of mind?” Answers to such questions can help discriminate among women who may prefer mastectomy over lumpectomy.

This type of assessment, both the knowledge and patients’ priorities can be done informally during the conversation, or administered as an instrument. Sepucha and colleagues have worked to develop decision quality instruments (DQIs) for breast cancer, and other common medical decisions\(^{(44-46)}\). The Breast Surgery DQI has three parts, a set of decision-specific knowledge items that are summed to a knowledge score, a set of items that ask about the interactions with health care providers, and a set of goals and concerns that are used to calculate the percentage of patients who received treatments that matched their goals. Annex 1 shows some of the knowledge questions and goals included in the survey instrument.

The responses can be used as a screen before a visit to diagnose gaps in patient understanding, assess patient priorities, and assess the patient’s attitudes on the risk-benefit profiles of treatments. If administered after a decision has been made, the DQI can be used to audit the quality of the decision and evaluate quality of decision support tools. Dartmouth Hitchcock Breast Center implemented a short screening version of the breast surgery DQI and found that with after integrating video-based decision aids that patients were consistently well informed, with more than 90% answering correctly that survival was the same with either surgery\(^{(47)}\). Further, they were able to document that treatments were being appropriately tailored to patients’ goals.

**Case Study**

The case study describes the implementation and evaluation of decision support tools for breast cancer patients at the Breast Cancer Center (BCC) at the
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University of California San Francisco (UCSF). Dr. Laura Esserman, Director of the BCC, has long championed the cause of shared decision making. Since the mid-1990s, Dr. Esserman has collaborated with the authors to study, implement, and evaluate decision and communication aids.

This collaboration was inspired by the identification of three problems during 23 focus groups involving 250 breast cancer survivors in 1994. The survivors said that newly diagnosed patients lacked access to good information; “froze up” during visits and did not ask important questions; and that even if they did ask questions, doctor responses went “in one ear and out the other.” The authors found and contributed to an evidence base suggesting that these needs could be addressed, in order, by decision aids, question prompting and coaching, and audio-recording and notetaking.

From 1998 to 2003, under the authors’ supervision, graduate students and staff at the UCSF BCC delivered communication aids, which included question-listing, note-taking, and audio-recording services to around 100 patients a year, and maintained a lending library of video-based decision aids that was accessed by a few dozen patients a year. In 2004, the Foundation for Informed Medical Decision Making (FIMDM) selected the UCSF BCC as a demonstration site and provided funding and other resources to support broader and deeper integration of decision support into routine clinical care.

The BCC is a busy academic cancer center. During the 2009 calendar year, BCC physicians saw 609 new patients during 1,322 new visits. The population is largely insured, with ethnic and racial diversity reflecting San Francisco’s demographics. The distributions of patient demographics, stage, and treatment choices are listed in Table 2.

The Decision Services leadership monitors and continuously improves the program’s performance. Here we report on three key aspects of Decision Services: (1) the reach, or how many eligible patients are contacted and invited to use the services; (2) the effectiveness, or how well the services improve decision making and communication including, knowledge, patient and provider satisfaction and decision outcomes; and (3) adoption, or how many patients and clinicians accept and use the services.

Reach is determined by the number of eligible patients contacted, the number of eligible visitors served (some patients have more than one visit), and the percent of total visits served. For Decision Services, eligibility is defined in terms of whether a patient has a scheduled appointment with a clinician to discuss treatment options for a confirmed diagnosis of breast cancer. The graph in Figure 1 shows the growth in reach for the decision aids and the delivery of the decision support, including decision and communication aids, is implemented with 2 full-time equivalent staff, in the form of 10 staff members, working one day a week each on decision services.

Staff members send decision aids to patients scheduled for a treatment decision making consultation with surgeons, plastic surgeons, and medical oncologists. Decision Services staff members also call the patients and offer to write down their question lists, take notes at the appointment, and make recordings of the patient-physician discussion.

The BCC formed an organizational unit called Decision Services with the purpose of promoting patient participation in treatment decisions. The operations are run by a part-time director (author JB), and 1.3 full-time equivalent staff to oversee training, service delivery, and data collection, analysis, and reporting for evaluation and quality assurance purposes.
communication aids as well as number of overall visits since the program’s first full year of operations.

The delivery of decision aids has grown rapidly and is now leveling off at about 75% of new patient visits. It is not expected to get much higher because the decision aids are not appropriate for all of patients (e.g. there is not a decision aid for patients with inflammatory breast cancer). The graph also provides a contrast between the delivery of decision aids, which is automated, with the delivery of communication aids (abbreviated QLARNT for Question-Listing,

**Table 2. Demographics and treatments rates for UCSF breast cancer patients in 2009.**

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>383 (63%)</td>
</tr>
<tr>
<td>Asian</td>
<td>124 (20%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>42 (7%)</td>
</tr>
<tr>
<td>African American</td>
<td>43 (7%)</td>
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<table>
<thead>
<tr>
<th>Insurance</th>
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<tr>
<td>Managed Care</td>
<td>369 (61%)</td>
</tr>
<tr>
<td>Medicare</td>
<td>226 (37%)</td>
</tr>
<tr>
<td>Self Pay</td>
<td>3 (1%)</td>
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<table>
<thead>
<tr>
<th>Stage of disease</th>
<th>N (%)</th>
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<tbody>
<tr>
<td>0</td>
<td>102 (20%)</td>
</tr>
<tr>
<td>1</td>
<td>188 (36%)</td>
</tr>
<tr>
<td>2</td>
<td>161 (31%)</td>
</tr>
<tr>
<td>3</td>
<td>49 (10%)</td>
</tr>
<tr>
<td>4</td>
<td>17 (3%)</td>
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<table>
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<tr>
<th>Surgery</th>
<th>N (%)</th>
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</thead>
<tbody>
<tr>
<td>Lumpectomy</td>
<td>270 (52%)</td>
</tr>
<tr>
<td>Mastectomy only</td>
<td>63 (12%)</td>
</tr>
<tr>
<td>Mastectomy and Reconstruction</td>
<td>138 (27%)</td>
</tr>
<tr>
<td>No Surgery</td>
<td>47 (9%)</td>
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</table>

<table>
<thead>
<tr>
<th>Radiation</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>183 (35%)</td>
</tr>
<tr>
<td>No</td>
<td>335 (65%)</td>
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<table>
<thead>
<tr>
<th>Chemotherapy</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No chemotherapy</td>
<td>310 (60%)</td>
</tr>
<tr>
<td>Adjuvant chemotherapy</td>
<td>144 (28%)</td>
</tr>
<tr>
<td>Neo-adjuvant</td>
<td>64 (12%)</td>
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<table>
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<tr>
<th>Hormonal therapy</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>185 (36%)</td>
</tr>
<tr>
<td>No</td>
<td>333 (64%)</td>
</tr>
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</table>
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Audio-Recording, and Note-Taking), which are subject to labor capacity constraints. In a flat-budget context, the reach of communication aids has increased from 17% to 26% through higher utilization of labor capacity. At current staffing levels, the maximum expected reach with these services is about 33%.

Effectiveness of the decision aids was determined by assessing patients’ knowledge and satisfaction. Over a three year period, we received completed responses from 549/1,533 visitors (35% response rate) and found that knowledge increased from an average of 45% (out of 100%) before viewing the decision aids to 74% after viewing the decisions aids (p<0.001). Patients were extremely satisfied with the decision aids and virtually all patients (96%) would recommend them to others.

The impact of the question-listing service was determined by the number of questions asked, patients’ confidence in asking questions, and patient satisfaction. The question-listing was associated with significant increases in the number of questions that patients had (8 before versus 24 after the session, p<0.001) and in patients’ confidence in asking (6.7/10 before versus 8.1/10 after, p<0.001). Patient satisfaction with the service was also high.

In addition to these quantitative measures, we invite patients to comment on the services. The following comments illustrate some typical patient reactions:

“I have not seen any other materials that have been so helpful and personal. The moderators in the video… are very knowledgeable, professional and compassionate. It also helps

Figure 1. Increase in reach for the decision and communication aids at the University of California San Francisco Breast Cancer Center over five years.

QLARNT=question listing, audio recording and note taking; DA= decision aid; N60s=new patient visits eligible for aids
tremendously to listen to women who have ‘been there’ and made their own decisions. Thank you for also including pictures of some of the final results after reconstructive surgery! ...Thank you for this service.”

– Patient who had viewed breast surgery, breast reconstruction and systemic therapy decision aid programs

“The question listing helped me focus on the things I had been thinking about but hadn’t written down. Having someone taking notes helped me enormously because I wasn’t anxious about the amount of information I was trying to take in – I knew that I would be able to review it.... It is an outstanding service.”

– Patient after receiving Communication aids

As shown in Figure 1, the adoption of decision aids in 2009-2010, was high reaching 1,023/1,355 eligible clinic visitors (75%). We contacted 1,124/1,355 (83%) of the visitors to offer assistance with question-listing, audio-recording, and note-taking. Of the 909 respondents, 607 accepted the communication aids (67%), while 28% declined and 5% were deemed ineligible after further review. Those who declined generally indicated that they did not need assistance with communication strategies because friends or family members were accompanying them to help with question-asking, audio-recording, and note-taking.

As a further indication of adoption, we surveyed patients 4-6 weeks after their visits to examine how many actually reviewed the aids. We received responses from 209/368 patients (57%) who received a decision aid and found that the majority viewed the videos (78%) and booklets (93%). We received responses from 158/319 patients (50%) who received communication aids and found that a majority reviewed the question list (68%), the consultation summary (83%), and the audiotaped recording of the consult (56%). For all the services, about half of the patients reported sharing them with others, and the overwhelming majority would recommend them to others.

Decision and communication aids can be integrated into routine clinical care with documented benefits for patients on educational outcomes. The evaluation results find similar benefits to those reported in randomized trials of decision and communication aids, providing evidence of effectiveness. Patients and physicians alike have embraced shared decision making in our clinic.

One emerging area of concern is the maintenance and updating of the decision aid content. As with most cancer centers, the Breast Care Center is adopting new evidence-based practices and some of these are not discussed in decision aids. For example, the decision aids do not cover newer techniques such as nipple-sparing mastectomies with breast reconstruction. The BCC physicians are exploring ways to supplement the packaged decision aids with additional materials.

**Conclusion**

Breast cancer patients are increasingly seeking more information and more participation in decisions about their care. The shift in decision making, from a more paternalistic approach where the doctor decides what to do, to a more shared approach represents a fundamental change in the way clinical decisions are made. Providers and cancer centers need to new tools, methods and metrics to respond to this new demand and ensure high quality of treatment decisions.

Many oncologists have already adopted tools to help their patients make more informed decisions. The types of
interventions described here, decision aids, question listing or prompt sheets and consultation summaries are fairly powerful tools that oncologists can use to improve the quality of decision making. In addition, incorporating measurement of patient knowledge and their goals and concerns will enable The tools are inexpensive (most are free), but oncologists wishing to implement them will have to invest some time in setting them up, integrating them into their practice and adapting them as practices change.

When newly diagnosed patients turn to cancer survivors for advice they often hear: “Learn about your condition; make a list of questions for your doctor; think about what’s important to you; take notes or bring someone to take notes for you; make a tape recording of your consultation.” Studies of these practices have shown that they improve the quality of decisions, in addition to improving health and quality of life outcomes. Cancer centers and cancer providers committed to improving the quality of care should consider implementing decision support tools to help ensure that their patients are informed and that the treatments chosen reflect patients’ preferences.

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Annex 1.

Selected items from the Breast Cancer Surgery Decision Quality Instrument.
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This set of questions asks about some facts that doctors think are important for patients to know about breast cancer. The correct answer to each question is based on medical research.

1. For most women with early breast cancer, how much would waiting 4 weeks to make a decision about surgery affect their chances of survival?
   - A lot
   - Some
   - A little or not at all

2. With treatment, about how many women diagnosed with early stage breast cancer will eventually die of breast cancer?
   - Most will die of breast cancer
   - About half will die of breast cancer
   - Most will die of something else

3. After which treatment is it more likely that women will need to have another operation to remove the tumor?
   - Lumpectomy
   - Mastectomy
   - Equally likely for both

4. On average, which women with early breast cancer live longer?
   - Women who have a mastectomy
   - Women who have lumpectomy and radiation
   - There is no difference

5. On average, which women have a higher chance of having cancer come back in the breast that has been treated?
   - Women who have a mastectomy
   - Women who have a lumpectomy and radiation
   - There is no difference

What Matters Most to You: This set of questions includes some reasons other women give for choosing their breast cancer surgery. We are interested in what is important to you. Please mark on a scale from 0 to 10, how important each of the following is to you for your decision about surgery.

How important is it to you to . . .
Keep your breast?
Remove your entire breast to gain peace of mind?
Avoid having radiation?
Relieve worries about getting breast cancer in the future?

<table>
<thead>
<tr>
<th>Not at all important</th>
<th>Very Important</th>
</tr>
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<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
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