Life After early Breast Cancer: Science, Perceptions & Communication Surrounding Risk of Recurrence (Life ABC) is supported by Novartis Oncology.
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Of women born in the United States today, 13.2% will be diagnosed with breast cancer at some point in their lives. Every three minutes in the U.S. a woman is diagnosed with breast cancer; one person dies of the disease every 14 minutes. Breast cancer accounts for one out of every three cancer diagnoses (excluding skin cancers) for women in the U.S.

As the nation’s only non-profit organization whose mission is to improve the health of all women through research, education and advocacy, the Society for Women’s Health Research (the Society) is keenly interested in education and research initiatives focused on women with breast cancer.

While advances in breast cancer treatment have increased the likelihood of survival, many breast cancer patients may still experience a recurrence of their disease. Because options exist to help reduce this possibility, concerns about women’s perceptions of their risk of recurrence—and how these perceptions affect communication with their health care professionals and the treatment choices they make—are important issues for breast cancer survivors.

The Society recently commissioned the Roper Organization (part of NOP World, a global research firm), to conduct a survey to identify how well women who are undergoing or have undergone treatment for breast cancer understand their risk of recurrence and whether they are communicating about this subject with their health care professionals. The telephone survey of 300 women with early breast cancer found that many women are concerned about risk of recurrence but are not yet communicating with their health care professionals about this topic. This is coupled with a strong desire on the part of the women surveyed for understandable information about their disease. These findings illustrate the critical need for communication and education to ensure that women who have had early breast cancer are doing everything they can to stay healthy and cancer free.
This report offers a timely and compelling look at current research on how women perceive their risk both during and after completing treatment, and identifies possible barriers that may be impeding a discussion between health care professionals and patients about the risk of breast cancer recurrence. While there is no universal answer—every woman’s risk of recurrence is different, and effective communication includes variable and highly individual elements—both patients’ and health care professionals’ awareness of the need for open dialogue surrounding the ongoing risk and prevention of breast cancer recurrence is imperative. Every step toward advancement of research and knowledge regarding breast cancer can mean improved chances of survival for more women and men around the world.

Sincerely,

Phyllis Greenberger, MSW
President and CEO
Society for Women’s Health Research

Founded in 1990, the Society brought to national attention the need for the appropriate inclusion of women in major medical research studies and the need for more information about conditions affecting women disproportionately, predominately, or differently than men. The Society advocates increased funding for research on women’s health; encourages the study of sex differences that may affect the prevention, diagnosis and treatment of disease; promotes the inclusion of women in medical research studies; and informs women, providers, policy makers and media about contemporary women’s health issues.
Breast cancer is the most common cancer among women (excluding skin cancers) and is the second leading cause of cancer deaths among women worldwide. Globally, more than 1.2 million people will be diagnosed with early breast cancer this year.4

The term “early breast cancer” refers to breast cancer in stages 0, I and II at the time of diagnosis. With stage 0, the cancer is non-invasive, meaning it has not spread to surrounding normal tissue (sometimes called carcinoma in-situ). In stage I cancer, the tumor is two centimeters in size or smaller and has not spread outside the breast. And, in stage II, either:

- There is no tumor in the breast, but cancer is found in the axillary lymph nodes (nodes under the arms); or,
- The tumor is two centimeters or smaller and has spread to the axillary lymph nodes; or,
- The tumor is two-to-five centimeters and has spread to the axillary lymph nodes; or,
- The tumor is larger than five centimeters and has not spread to the axillary lymph nodes or;5
- The number of lymph nodes involved with cancer is not more than three.6

In early breast cancer, the tumor is usually removed surgically, either with breast-conserving surgery (lumpectomy) or by removing the breast (mastectomy). Based on new technologies for early detection, between 70 and 75% of women diagnosed with breast cancer are possible candidates for lumpectomy.7 Research shows that women with early-stage breast cancer who have breast-sparing surgery along with radiation have similar survival rates to those who have a mastectomy.5

But despite these promising results, microscopic deposits of the disease, undetectable by current diagnostic tools, may sometimes remain behind. These deposits may, after several years or even several decades, develop into a clinically detectable recurrence of the disease. For patients who are considered at intermediate or high risk for recurrence, health care professionals will often offer post-surgical treatment (adjuvant therapy) as an option to help reduce this risk. However, recent research indicates that some women who are considered at “low risk” could also benefit from adjuvant cancer therapy.9-14
At present, women with breast cancer have numerous treatment options available to them. However, this report only focuses on women with early breast cancer who have received standard adjuvant hormonal therapy, tamoxifen, which in North America is the most commonly prescribed adjuvant therapy.

A retrospective observational study conducted in British Columbia revealed that since the introduction of adjuvant therapy into standard clinical practice, there has been a trend toward superior outcomes in women with breast cancer treated with adjuvant therapy compared to women treated in earlier decades, before adjuvant therapy was widely practiced.\textsuperscript{15}

Additionally, in a meta-analysis of more than 37,000 women who have been in randomized trials of adjuvant tamoxifen and/or chemotherapy, data showed that overall survival rates improved significantly when the use of adjuvant therapy became standard practice.\textsuperscript{9} However, data show that many women still face the possibility of their cancer returning.

Added to these research findings, a new survey conducted by the Roper organization among 300 breast cancer patients reveals that women are worried about their risk of recurrence, but many have not discussed these concerns with their health care professionals. Also, risk communication research shows that even when patients have these discussions with health care professionals, there can be serious gaps in the communication process that leave women without the information they need.

Therefore, effective and comprehensive communication between patients and health care professionals is integral for conveying a woman’s risk of recurrence and thus ensuring proper treatment of early breast cancer. However, a critical gap remains in the understanding of, and communication about, risk of recurrence in women with early breast cancer after they have successfully been treated with surgery. This lack of understanding factors into patient and health care professional treatment decisions, and warrants further exploration to ensure long-term patient health and survival.
Purpose of Report

This report is the foundation for *Life After early Breast Cancer: Improving Your Chance of Staying Cancer Free (Life ABC)*, a nationwide public education campaign conducted by the Society for Women's Health Research (the Society).* Following a review of the scientific literature addressing the prevention, diagnosis and treatment of early breast cancer with a special focus on the prevalence/impact of recurrence of the disease, the Society commissioned a survey of the attitudes and beliefs of breast cancer patients regarding their risk of recurrence, and their discussions of that risk with their health care professionals.

Taken together, these findings provide a framework for exploring the perceptions of risk of recurrence in women who have undergone treatment for early breast cancer. As such, the report touches on the complexities of risk communication that may contribute to these perceptions. The report is intended as a platform from which to launch a discussion about improvements in the communication process between health care professionals and women with breast cancer that might lead to improved treatment programs. It is not intended to provide a comprehensive overview of breast cancer or clinical recommendations for its management and treatment. This report was prepared for patient advocacy groups and health care professionals to be disseminated to their constituents.

Because this report is intended for the use of patient advocacy groups and health care professionals to guide a discussion on risk of recurrence, the Society also enlisted leading breast cancer advocates and cancer information specialists to review the report.

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RISK OF RECURRENCE

Clinical management of patients with early breast cancer is determined on an individual basis, taking into account many factors, including the risk of cancer recurrence. The clinical management of breast cancer is directly linked to pathological assessment of the cancer so accurate pathological interpretation of the breast cancer specimen is vital.

Health care professionals use these prognostic factors to help determine recommendations for appropriate adjuvant therapy and whether additional treatment should be considered after adjuvant therapy has been completed.11, 16, 17

In 2005, the St. Gallen International Consensus Panel, a panel of experts in the field of early breast cancer, revisited risk categories for patients with ER/PgR-positive early breast cancer and determined that to qualify as “minimal-risk” [also called low-risk], all of the following criteria need to apply: cancer has not spread to the lymph nodes; tumor is <2 cm in greatest dimension; nuclei are small, with little increase or variation in size compared with breast epithelial cell nuclei, regular outlines, uniformity of nuclear chromatin; no cancer cells have invaded the blood or lymphatic vessels and cancer does not use the HER2/neu pathway to grow.

Better understanding of actual ongoing risk in all patients, including “low-risk” patient populations, is critical for optimizing treatment decisions. In this paper we will discuss some of the latest data that have emerged surrounding the risk women with early breast cancer face in terms of their disease returning.

Clinical Research

Node-negative status at diagnosis has commonly been associated with a favorable patient outcome. However, long-term risk of recurrence and death are not well understood. Many current studies support the notion that there is a risk of recurrence for women with early breast cancer regardless of nodal status, estrogen receptor status, age, chemotherapy regimen, time on tamoxifen or time from initial diagnosis.9-14

Common factors have been identified for predicting risk of recurrence in patients with breast cancer. They include:

- **Lymph Node Involvement**
  - Whether the tumor has spread to the lymph nodes at the time of diagnosis (node-positive) and, importantly, the number of lymph nodes in which cancer has been found.

- **Tumor Size**
  - Factor in determining the stage of breast cancer.

- **Histologic Grade**
  - Grade is a calculation based on how abnormal the cancer cells look under a microscope and how fast they are growing. There are 3 features when determining a cancer’s grade: (1) the rate of cell division, (2) percentage of cancer composed of tubular structures, and (3) change in cell size and uniformity. If a tumor has been determined to be Grade 3 then there is a higher risk of recurrence than if the tumor was determined to be Grade 1.

- **HER2/neu (a growth-promoting protein) Status**
  - Gene that helps the growth of cells, how they divide, and repair themselves. Positive or negative HER2/neu is important in the control of abnormal or defective cells that could become cancerous and might have implications for treatment.

- **Lymphatic Vessel Invasion (LVI)**
  - When pathologists look directly at the cancer under a microscope they determine whether cancer cells are found in the lymphatic vessels within the cancer itself.

- **Hormone Receptor Status**
  - This status reflects whether the cancer is estrogen receptor positive (ER+) or not (ER-) or progesterone receptor positive (PgR+) or not (PgR-). This status may have some prognostic information and, at this time, is used to plan treatment.

In 2005, the St. Gallen International Consensus Panel, a panel of experts in the field of early breast cancer, revisited risk categories for patients with ER/PgR-positive early breast cancer and determined that to qualify as “minimal-risk” [also called low-risk], all of the following criteria need to apply: cancer has not spread to the lymph nodes; tumor is <2 cm in greatest dimension; nuclei are small, with little increase or variation in size compared with breast epithelial cell nuclei, regular outlines, uniformity of nuclear chromatin; no cancer cells have invaded the blood or lymphatic vessels and cancer does not use the HER2/neu pathway to grow.

Better understanding of actual ongoing risk in all patients, including “low-risk” patient populations, is critical for optimizing treatment decisions. In this paper we will discuss some of the latest data that have emerged surrounding the risk women with early breast cancer face in terms of their disease returning.
Ongoing Risk

Many people have the misconception that after successful initial treatment, patients with early breast cancer who remain disease free for five years or more (according to existing tests) are unlikely to experience a recurrence of their cancer. However, recurrences can occur after five years.

In a meta-analysis (from seven different studies) of more than 3,500 patients who had received some type of post-surgical adjuvant therapy for breast cancer, risk of cancer recurrence was greatest during the first two years following surgery. After this period, the research showed a steady decrease in the risk of recurrence until year five when the risk of recurrence declined slowly and averaged 4.3% per year. But a substantial proportion of breast cancer recurrences seen in this study occurred more than five years after surgery, between years six and 12, even in patients who typically would be considered at low risk for recurrence because their cancer had not spread to the lymph nodes at the time of diagnosis (node-negative). What this research indicates is that through at least 12 years of follow-up, the risk of breast cancer recurrence remains appreciable and even some patients considered low risk have some risk of the cancer coming back.

Another meta-analysis, this one of nearly 37,000 women with early breast cancer, conducted by the Early Breast Cancer Trialists’ Collaborative Group, found:

- Through the first 10 years after diagnosis, the cumulative incidence of recurrence and breast cancer-related deaths continued to increase, with a substantial portion of recurrences and breast-cancer related deaths occurring beyond five years after diagnosis.

- The recurrence rate among patients who did not receive adjuvant hormonal therapy was nearly 50% in node-positive patients and 32.4% in node-negative patients throughout the first 10 years after diagnosis.
These data showed that some years of adjuvant tamoxifen treatment substantially improved the 10-year survival of women with estrogen receptor-positive (ER+) tumors and of women whose tumors are of unknown ER status, even in women who had node-negative disease.9

Another analysis of recurrence among ER+ patients found that use of tamoxifen therapy significantly improved patient outcomes in a population considered to be at minimal risk prior to this trial. However, even with adjuvant therapy, more than 20% of node-negative patients had their disease recur within 15 years after diagnosis.11

Confirming these findings, a recent study showed that even for small tumors in the lowest risk category, the 10-year risk of breast cancer recurrence was as high as 12% in the absence of adjuvant therapy. Additionally in the absence of adjuvant therapy, even in the lowest risk category, the 10-year risk of breast cancer-related death is high, at 7%.14

Another study showed that more than half of all breast cancer recurrences and two-thirds of all breast cancer deaths occur after completion of five years of standard tamoxifen therapy.19

A study evaluating the risk of breast cancer recurrence following adjuvant therapy in 2,420 patients with early breast cancer showed that there was a substantial and continuing risk of recurrence long after completion of five years of standard adjuvant treatment.20 Additionally, after the first five years, there were similar proportional rates of recurrence for node-negative and node-positive breast cancer patients.20 Data from the National Surgical Adjuvant Breast and Bowel Project B-14 trial showed, however, that continued use of tamoxifen after five years was associated with an increase in serious adverse events, but no further efficacy benefits.11

As part of the treatment process, the risks and benefits of possible treatment options are necessarily discussed. In terms of the adjuvant therapy most commonly used, tamoxifen, the American Cancer Society indicated that tamoxifen can increase the risk of developing cancer of the lining of the uterus (endometrial cancer). This cancer is usually diagnosed at a very early stage and is generally curable by surgery. Tamoxifen can also increase the risk of uterine sarcoma, a rare cancer of the connective tissue of the uterus. Blood clots are another serious side effect of tamoxifen. Other side effects may include weight gain (although recent studies have not found this), hot flashes, vaginal discharge and mood swings.21
Many studies conducted in breast cancer reveal that most adjuvant therapies are essential tools in the fight against breast cancer as they decrease the risk of recurrence by at least one-third. But the ongoing risk of recurrence in patients with very small tumors and no nodal involvement points to the need to continue research into even greater improvements in ways to determine accurately a woman’s risk of recurrence in order to evaluate the best treatment options available. Furthermore, it is essential that health care professionals communicate these findings with their patients while discussing treatment options.
Purpose
The in-depth survey commissioned by the Society and administered by the Roper Organization was conducted between February 18th and March 28th, 2005 via telephone among a national sample of 300 post-menopausal women diagnosed with early breast cancer. The women met the following criteria:

- Had completed three or more years of adjuvant hormonal therapy (such as tamoxifen), and are still receiving that therapy, or
- Had completed five or more years of adjuvant hormonal therapy (such as tamoxifen) within the past two years.

To identify these respondents, Roper used a list of women pre-identified as having breast cancer based on a random sampling of households. This panel is balanced demographically to represent all households in the United States for a wide range of doctor-diagnosed health conditions, including breast cancer. A sample of women diagnosed by a health care professional as having breast cancer was drawn from this frame on a random basis and subsequently screened by telephone to identify those breast cancer patients who met one of the above eligibility criteria.

Due to the low incidence of eligibility, the sample of 300 also included 30 eligible women who were recruited by a national sample of oncologists. The women then voluntarily called Roper using an 800 number provided to them by their physician. This procedure maintained physician-patient confidentiality.

Of the total 300 completed telephone interviews, 177 were with women nearing completion of the therapy and 123 were women who completed therapy.

The sampling error for those currently on therapy is +/-7%. For those who completed the therapy, the margin of sampling error is +/-9%.

Considerations
This survey is subjective and based on the opinions of the patients who participated. This report interprets their results in the context of other published research.
Majority of patients look to the future

When asked, “As a woman who has been treated for breast cancer, how would you describe yourself now?” 71% of women with early breast cancer who completed adjuvant hormonal therapy (such as tamoxifen) and 72% of women who are currently receiving adjuvant hormonal therapy considered themselves a “breast cancer survivor.” Only a minority, 34% and 24%, respectively, described themselves as “cancer free.”

**Most Consider Themselves Breast Cancer Survivors**

<table>
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<th>% say would describe themselves this way now</th>
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<tr>
<td>Is a breast cancer survivor</td>
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<td>72%</td>
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<tr>
<td>71%</td>
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<tr>
<td>Is cancer free</td>
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<tr>
<td>24%</td>
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<tr>
<td>34%</td>
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<tr>
<td>Had breast cancer</td>
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<tr>
<td>23%</td>
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<tr>
<td>24%</td>
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<tr>
<td>Has breast cancer</td>
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<tr>
<td>1%</td>
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<td>3%</td>
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Many patients try not to focus on their cancer after completing initial treatment

Approximately 77% of women with early breast cancer who completed adjuvant hormonal therapy and 79% of women now receiving adjuvant hormonal therapy indicated they “try not to think about cancer too much.”

But this does not necessarily mean that these women do not worry about their cancer returning. In this survey, 50% of women with early breast cancer who completed adjuvant hormonal therapy and 57% of women who are currently receiving adjuvant hormonal therapy indicated that they “still worry about [their] cancer returning in the future.”

Supporting this finding is data from at least one other unpublished study. The study is based on a pilot survey of 72 Stage I, II or III breast cancer survivors where the length of time since participants had completed treatment for early breast cancer varied. However, the results indicate that a majority of the women continue to worry, to some degree, about their risk of breast cancer coming back.

Specifically, the women in the survey were asked: “Over the past seven days, how many days have you spent at least part of the day worried about getting breast cancer again?”

Of the women surveyed, 33% worried for three or more days per week about their breast cancer returning.

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<th>Received Tamoxifen</th>
<th>Completed Tamoxifen</th>
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<tr>
<td>You try not to think about cancer too much</td>
<td>79%</td>
<td>77%</td>
</tr>
<tr>
<td>You still worry about your cancer returning in the future</td>
<td>57%</td>
<td>50%</td>
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A significant number of women haven’t discussed risk of recurrence with their health care professionals

According to the Roper survey, nearly one-quarter of women with early breast cancer who completed adjuvant hormonal therapy and 40% of the women who are still receiving adjuvant hormonal therapy say they have never discussed with their health care professional their risk of breast cancer coming back once [they] have completed five years of adjuvant hormonal therapy.22

However, when asked how they might feel after finishing five years of adjuvant hormonal therapy, 95% of women who completed adjuvant hormonal therapy and 97% of women still receiving adjuvant hormonal therapy say they want to learn everything they can about preventing recurrence.22

Also, 84% of women who completed adjuvant hormonal therapy and 87% of women who are still receiving adjuvant hormonal therapy believe that it is “critical” or “very important” that they do everything they can to reduce the risk of their breast cancer returning.22

Most Consider It Important To Do Everything They Can To Reduce Risk of Recurrence
% say it is important to do everything you can to reduce the risk of breast cancer returning

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<th>Critical</th>
<th>Very important, but not critical</th>
<th>Somewhat important</th>
<th></th>
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<tbody>
<tr>
<td>Receiving Tamoxifen</td>
<td>34%</td>
<td>53%</td>
<td>11%</td>
<td>97%</td>
</tr>
<tr>
<td>Completed Tamoxifen</td>
<td>24%</td>
<td>60%</td>
<td>11%</td>
<td>95%</td>
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Majority of women do rely on their health care professionals to help them weigh the pros and cons of new treatment options

Of the women surveyed by Roper, 93% with early breast cancer who completed adjuvant hormonal therapy and 94% of those still receiving adjuvant hormonal therapy, say that they depend on their doctor to help them evaluate the pros and cons of new treatment options.22

A majority of women don’t have complete information about the significance of risk of recurrence

More than half of the women surveyed do not realize that approximately one-third of women with hormone dependent early breast cancer will experience a recurrence.22

Additionally, 42% of women who completed adjuvant hormonal therapy and 50% of those still receiving adjuvant hormonal therapy did not know that more than half of recurrences occur five years or more after surgery.22

Many Are Not Well Informed About Recurrence

% who incorrectly believe the following to be false or don’t know

These survey results clearly demonstrate that women who have had early breast cancer are generally positive about their future but still worry about the chance that their cancer might come back. They recognize that they may be at ongoing risk for recurrence, rely heavily on health care professionals when making choices regarding treatment, but are not currently getting the information they need so that together with their health care professionals, they are to make informed decisions about prevention of breast cancer recurrence. Clearly, there are gaps and challenges in the communication process. These gaps must be understood and overcome. We explore the complexities of some of these issues in the next section.
Communication between health care professionals and women with breast cancer affects all aspects of the women’s treatment program. It is clear that the understanding of, and communication about, risk of cancer recurrence is a difficult, yet fundamental, aspect of treatment decision making for women with breast cancer and health care professionals working with them. But research suggests there are significant gaps between the intended message and the message received by patients in the physician-patient communication process.24, 25

Before addressing risk communication between patients and their health care professionals, it is important to contextualize this evolving relationship. Historically, health care professionals were viewed, by themselves and by patients, rather “paternally” as the keepers of information and the purveyors of treatment decisions—patients’ medical decisions were made by physicians without much discussion with the patients.26-28 In fact, in 1961, 90% of health care professionals surveyed indicated a preference for withholding information from cancer patients about their diagnoses.29 In sharp contrast, nearly all health care professionals (97%) surveyed with the same questionnaire in 1977 said they would tell their patients the diagnosis.30 This reflects the significant shift in the way the relationship between health care professionals and patients is viewed in recent years, particularly the degree to which patients are informed and involved in their medical decisions. Ethical, legal and social movements now require that health care professionals communicate with, and provide information to patients so they are in a position to participate in informed decision making about their health care.26

However, there are discrepancies in the research regarding the actual role patients wish to play in the decision-making process. One study showed that 63% of cancer patients surveyed felt the physician should take primary responsibility for decision making, while 27% believed it should be a shared process, and only 10% felt they, the patients, should have a major role.26 As with other studies, this research shows that patients have a relatively high desire for information, even though they may express the wish not to be responsible for decisions.26, 31-33
In direct contrast a study looking specifically at women with breast cancer found that 22% of women wanted to select their own cancer treatment, 44% wanted to select their treatment collaboratively with their physicians and 34% wanted to delegate this responsibility to their physicians. This suggests that, in fact, women with breast cancer do not want a passive role in their treatment, but that a majority of them wish to work collaboratively with health care professionals to determine their best course of treatment. However, this research finds that older patients, on average, do not want as much information or control compared to their younger counterparts. The data have been confirmed through other studies.

A thorough review of the contradictory findings in studies regarding patient participation in decision making can be found in Guadagnoli and Ward's 1998 paper, “Patient Participation and Decision-Making.” Researchers suggested that part of this discrepancy may exist because many studies regarding making medical decisions did not distinguish sufficiently between problem solving (identifying the single correct solution) and decision making (helping to select the most desired bundle of outcomes). The researchers argued that problem-solving tasks require both a knowledge base and a set of decision-making skills not only to identify the possible alternatives but the probabilities of each likely outcome. This task requires an expertise that allows patients only a limited role for involvement. Further, the researchers found that while patients do not want to be involved in the problem-solving tasks, few wished to relinquish the decision-making control entirely to their physicians. In fact, the final conclusion of Guadagnoli and Ward's review of the research is that patients want to be informed of treatment alternatives and that they want to be involved in treatment decisions when there is more than one effective alternative available.

Despite the shift towards more patient involvement and autonomy in the decision-making process, patients are still strongly influenced by physician communications and recommendations. A recent study published in *Medical Decision Making* found that patients’ hypothetical treatment decisions were significantly swayed by the manner in which health care professionals make their recommendations (p<0.0001). Patients who chose the treatment offering maximum benefit were more likely to alter their decision if the physician recommended against it, compared to scenarios in which the physician made no recommendation (p<0.0001).
Further, a study by Siminoff and Fetting found that breast cancer patients were strongly influenced by health care professionals’ recommendations when it came to actual treatment decisions. These results indicate that health care professionals’ recommendations significantly affect patient choices when it comes to their treatment decisions, even when the recommendations go against what is “best” and against what the patient would otherwise prefer. In fact, the final recommendation of the physician is often the best predictor of the patient’s choice of therapy. This is a very important finding in terms of communication between health care professionals and patients, as health care professionals need to understand the way in which patients view their role when providing information. If patients look to the health care professionals for information to make their own decision, it is essential that these professionals provide all of the information possible to help patients make educated decisions and understand their alternatives and their risks.

Questions still remain, however, regarding the true link between the patient’s desire for and provision of information and his or her ultimate involvement in the decision-making process.

For the purposes of this paper, we need to explore the elements of communication that might lead to gaps between a patient’s understanding of his or her risk of recurrence and how it is being communicated by the health care professional. Because of this lack of understanding, there may be a vast difference between the estimated magnitude of risk and the patient’s perceptions, interpretations and beliefs about those risks.

Understanding Risk
The two main assumptions underlying risk communication research are that patients lack a clear understanding of cancer risks and that if patients were well-informed about their risks, they could make informed, prudent choices regarding treatment and lifestyle changes.

The two components to an understanding of risk are the probability and seriousness of the threat, and how the threat can be controlled. Patients may resist discussions surrounding risk of recurrence, thus keeping themselves from understanding the full import of their risk and their options for combating that risk. Even when patients do discuss risk, many studies have shown that they tend to have inaccurate perceptions of their risk. These inaccurate risk perceptions can come in two forms: optimistic bias and pessimistic bias.
On one hand is an optimistic bias. As a leading risk communication investigator noted about this phenomenon, “Risk perception is not an unbiased appraisal of information, but rather an attempt to seek the most comforting view of one’s personal vulnerability that fits within the bounds of the evidence.”

Studies indicate that when comparing themselves to others, individuals with an “optimistic bias” will often claim that they are at lower risk of bad outcomes and higher probability of good outcomes than the average person, particularly when they believe a particular hazard is preventable. These optimistic biases seem to be unrelated to age, sex, level of education or occupation.

On the other hand, some studies have found that many people overestimate their cancer risk, thereby demonstrating a “pessimistic bias,” meaning they believe they have a greater absolute risk of recurrence than they actually do. For example, all participants in one study overestimated their lifetime risk of getting breast cancer. While another study of women with ductal carcinoma in situ, an early, non-invasive stage of breast cancer, perceived their risk of recurrence and dying from breast cancer as similar to that of women with early stage invasive cancer—an overestimation of their true risk.

Because of their overestimation of risk, the women studied also indicated that they suffered psychological distress because of this belief. Moreover, many patients, especially those who are more worried, maintain their elevated perception of their risk of cancer even when told by trusted health care professionals that their risk is lower than they thought.

There are ways of resolving these apparently contradictory results regarding optimistic and pessimistic risk perception: first, it could be that individuals overestimate the risk of bad outcomes, but do so more for others than for themselves. Second, when estimating the likelihood of unlikely events (which many of the health risks studied are), respondents tend to overestimate rather than underestimate. If the true risk is 10%, for example, there is much more room to move up than to move down, so overestimating is more likely.

Little is understood about how women with breast cancer or other diseases process risk information over time and how this processing may differ as a function of risk status, individual differences, social context, as well as other factors. Decisions and behavior are not determined by knowledge alone—there are many other powerful factors involved, including emotions, values, social pressures, environmental barriers and economic realities. Education does not necessarily correlate with wise decisions. Researchers have also documented that patients generally have considerable difficulty understanding and working with risk calculations and probabilities when health care professionals provide them, an important element for understanding risk.
Additionally, a survey of breast cancer patients, published in the *Journal of Clinical Oncology* in 1998, showed that only 39% of the women recalled receiving estimates of their risk and only 31% of women received a comparison of their risk with and without adjuvant therapy.55 But women’s perceptions and ability to recall risk information is only half of the challenge.

**Communicating Risk**

Effectively communicating any cancer risk information is fundamentally challenging for health care professionals as well. Not only do health care professionals have to communicate often contradictory and inconclusive information thoroughly and effectively, but they must also understand how the patient perceives the information so that misperceptions can be corrected.55 This difficulty is highlighted by current data from genetic counseling, which show that even with communication in one-on-one settings there are still few perfect matches between the message communicated and the message received.56

The way in which health care professionals present cancer risk information is critical to patient understanding and acceptance of the information.57 Because it is difficult to convert population-based estimates of cancer risk to precise statements of individual risk, it is difficult to ensure that “actual risk” is effectively communicated and accurately perceived.58 Additionally, evaluation of cancer risk based on all of the available scientific evidence does not guarantee the predicted clinical outcome. Currently, there is a considerable unmet need in terms of cancer risk communication research to help health care professionals utilize best practices to most effectively impart highly scientific, as well as personally relevant, information to patients.45

Health care professionals tend to use specialized language (or jargon) that patients find difficult to understand.59 This can include using acronyms, words and phrases that represent biological conditions, clinical procedures, laboratory results, etc.39 Many experts use the term “risk” as a technical term that refers to a particular known probability while the general public attaches many different meanings to the term, such as possibility of loss or injury; level or degree of danger; and others.
The emotional element, as well, isn’t relegated entirely to the patient “side” of the communication process. Research has found that health care professionals often base their communication of risk on emotion and personal conviction rather than the outcomes of scientific studies. Studies have shown that health care professionals find the communication of bad news emotionally difficult, and that this difficulty affects their method of imparting information.60

The various elements that contribute to any communication, particularly something as important as risk of recurrence communication, are important to consider. As Dr. Richard Klausner of the National Institutes of Health said, “We know far less about how to communicate risks than we know about how to calculate them.”61 Thus improving the communication practices by health care professionals surrounding risk of breast cancer recurrence is a fundamental and integral element of providing the best possible care for patients. This is particularly apparent given that a number of studies have demonstrated a correlation between effective physician-patient communication and improved patient health outcomes.62

While there are still many questions regarding the best means for sensitively and effectively communicating cancer risk information, studies have begun to focus on potential tools and communication strategies that health care professionals might use to overcome some of the difficulties surrounding risk communication. Based on a review of the empirical research regarding approaches to communicating health risk information, researchers determined that people do not tend to respond consistently to communication strategies that rely on the presentation of numerical risk information as the sole tool. Specifically, people will not always respond to a given probability in the same way—10% risk is sometimes perceived differently if it is presented as a percentage or an odds ratio or if it is presented numerically or pictorially.63 People have a difficult time interpreting statistical information identifying their risk.

In one study, researchers found that combining tailored print communications and a call from a telephone counselor succeeded in bringing women’s perceptions about developing breast cancer (the women studied did not have breast cancer) more accurately in line with their actual risk when compared with women who received either tailored printed information alone or no information.64 This is just one of numerous studies that are being funded by organizations such as the U.S. National Institutes of Health, in an attempt to close the gap in communicating cancer risk.
Research, as discussed in this report, clearly shows that cancer recurrence is an important issue for women who have had early breast cancer. It is critical that women who have had early breast cancer discuss their risk of recurrence frankly and completely with their health care professionals. Some advocates of women with breast cancer recommend that this discussion take place frequently and as early as possible so that it becomes an integral part of the entire treatment and wellness program, rather than a frightening “add on.” But it is important to remember that given the complexities of communication about the risk of breast cancer recurrence, the onus for this discussion does not only rest with women, but with health care professionals as well if truly open and informed communication is to take place. Additionally, research shows that patients experience health benefits from an engagement in the process with their health care professional that leads to an agreed management plan.62

If women with breast cancer are to be active and informed participants in the decision-making process, they must understand their prognosis, the probable benefit of all of the given therapy options available to them, as well as the cost and potential side effects of these therapies.55 Treatment programs are entirely individual. Each woman, with the help of her health care professionals, needs to be armed with her personal risk information if she is to work collaboratively with her physicians to make informed decisions about treatment. Without an understanding of risk, the full spectrum of treatment options might not be considered. Therefore, it is essential to understand how risk is being communicated and how it is being perceived in order to create models that will best serve patient and physician decision making around cancer, and in this discussion, early breast cancer. Women should be encouraged and empowered to talk to their medical oncologist, in particular, about steps they can take to prevent a recurrence.

According to the Roper survey, when gathering information about risk of recurrence, many women look to magazines and newspapers, the Internet and medical references to find information beyond that which their health care professional provided. Only a small percentage look to support groups and/or cancer societies.22 However, since technical information provided to women with early breast cancer from some of these sources may not provide the most comprehensive and balanced information, it is important to find ways to reach women with early breast cancer through a range of information channels. As such, tools such as the following, which will be located on http://www.lifeabc.org/ may help women seeking information participate even more effectively in their treatment.
To help prevent breast cancer and recurrence, it is important for all women to maintain a healthy lifestyle. Many factors contribute to breast cancer recurrence; therefore, the risk of recurrence is different for every woman. However, there are steps that all breast cancer patients can take that may increase their chances of remaining cancer free. The following checklist includes some of the important steps that may improve a woman's chance of remaining cancer free.

- **Eat a healthy diet and maintain a normal weight**
  - Follow a balanced diet containing the main food groups
    - Servings depend on your age, sex and physical activity
  - Eat whole grain foods such as:
    - whole-wheat flour
    - oatmeal
    - whole cornmeal
    - brown rice
  - Take a daily multivitamin
  - Limit alcohol intake
  - Limit saturated and trans fat intake

- **Begin an exercise program, at least three times a week. But be sure to discuss any exercise program with your health care professional before you start. Exercise can include**
  - Walking around the neighborhood
  - Swimming
  - Playing tennis with a friend
  - Joining a gym
  - Taking dance classes
  - Taking the stairs rather than the elevator
  - Parking a little farther away from your destination so you have to walk a little more

- **Examine the stresses in your life and find ways to reduce them if possible**
  - Daily meditation or regular exercise can help
  - Taking a yoga or tai chi class can help

- **Learn to care for yourself the way you care for others**

- **Tap into a support network—whatever you are comfortable with, such as friends, family, spouse/partner, spiritual community, online discussion groups, or others**

- **Develop a regular schedule for follow-up office visits with your health care professional**
  - Complete physical examination every 4 to 6 months for the first 5 years following treatment; then every 12 months
  - Annual mammograms
  - Monthly self-examinations of both breasts
  - Annual pelvic exam

- **Remain positive during this experience**
  - Measure what you have learned about yourself

- **Concentrate on what changes you can make to improve your quality of life**
QUESTIONS TO ASK YOUR HEALTH CARE PROFESSIONAL

About breast cancer risk:
- In what stage would you classify my breast cancer?
- What is my nodal status, and how does it affect my risk of recurrence?
- Am I estrogen receptor-positive or negative?
- Am I HER2/neu positive or negative?
- Can you talk to me about my personal risk of recurrence?

About reducing recurrence:
- What can I do to help prevent a recurrence of my cancer?
- How often should I visit you and for what types of exams (physicals, breast exams, checkups, etc.)?
- What cancer screening tests (e.g., mammography) should I have and how often?
- Should I consult a nutritionist about changes in my diet?
- When can I begin a regular exercise program?

About treatment:
- After I finish my treatment, what kind of follow-up care will I receive? For what length of time?
- What symptoms should I be on the lookout for that might mean that my cancer has returned?
- Will the treatment affect me sexually (reduction in sex drive, ability to have children)?
- Are there any long-term side effects of my treatment of which I should be aware?
- Am I at risk for any other cancers and what can I do to reduce that risk?

While communication about the risk of recurrence is difficult, it is necessary for the delivery of optimal care. Therefore, it is hoped that the discussion that will surround this report will serve to generate even more tools that can help women and health care professionals engage in this important discussion.
Endnotes

6 Vadhat L, MD, director of the Breast Cancer Research Program and Associate Professor of Clinical Medicine, Weill Medical College of Cornell University. Provided April 27, 2005.
7 National Women’s Health Information Center. Why would any woman pick mastectomy if the survival rate is the same? Accessed April 12, 2005. Available at: http://www.4woman.gov/faq/earlybc.htm.
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