

# Survey of Women's Experience With Breast Biopsy

Prepared For:

NABCO (the National Alliance of  
Breast Cancer Organizations)

and

Ethicon Endo-Surgery, Inc.  
a Johnson and Johnson company

September 1998

R O P E R  
S T A R C H

TURNING DATA INTO INTELLIGENCE WORLDWIDE

## INTRODUCTION AND METHODOLOGY

The Survey of Women's Experience With Breast Biopsy was conducted on behalf of NABCO (the National Alliance of Breast Cancer Organizations) and Ethicon Endo-Surgery, a Johnson and Johnson company, in order to gain an understanding of the biopsy experience among women who have undergone a biopsy within the past three years. Specific goals of the survey included documenting the types of biopsies performed, the events leading up to the decision to have a biopsy, and assessing women's levels of understanding with respect to specific aspects of the biopsy. Additionally, the purpose of the survey was to assess the emotional impact of the biopsy - including the waiting period and the procedure itself - on a woman's life.

The survey was conducted in two parts. Screening to locate women who had a breast biopsy within the past three years was conducted using a nationally-representative omnibus questionnaire mailed to 50,000 U.S. households. Specific questions included:

- In the past three years, has any female in your household had a biopsy of the breast?
- Was the result malignant or benign?

In the second phase of the study, follow-up telephone interviews were conducted between August 3, 1998 and August 23, 1998 with women who had a breast biopsy within the past three years. Additional screening was conducted during the interview to eliminate any woman who had a fine needle or cyst aspiration procedure; these are technically not biopsy procedures. Through this screening 65 women were disqualified.

In total, 250 interviews were completed among women who had either a surgical biopsy or other minimally invasive biopsy, including 200 with women whose biopsy result was benign, and 50 interviews with women whose result was malignant. The end sample was comprised as follows: 26% ages 45 or under, 49% ages 45-64, and 24% ages 65 or older; 92% White, 2% African American, and 5% other. Given that the median age of onset of breast cancer in the U.S. is 64, this may suggest some bias in this sample of women who have had a breast biopsy. And, compared to the general population, this sample is mostly White, possibly suggesting some bias in this sample.

The findings presented in this report, though not statistically projectable to the entire population, are representative of women who have undergone a biopsy of the breast. The margin of sampling error is +/- six percentage points on the totals.

## OVERVIEW OF FINDINGS

Data from this landmark survey among women who have had a recent breast biopsy present findings that are encouraging, while at the same time indicating the need for change with respect to the way women learn about and undergo breast biopsies.

The good news is that more than half of women (56%) report their breast abnormality was first discovered during a routine mammogram, indicating that both women and their physicians recognize the importance of this diagnostic device as a tool for the early detection and treatment of breast cancer. And, once they become aware of something suspicious, many physicians schedule additional diagnostic procedures including mammogram (70%), a second opinion or visit to the specialist (54%), or ultrasound (36%).

Upon learning they have a suspicious finding, most women (92%) experience some degree of fear or stress as they prepare for their biopsy. Not surprisingly, fear of cancer fuels this dread, even though three-quarters of women were told their outcome was likely to be benign. But interestingly, once their personal crisis has passed, the biopsy is over, and time has gone by, very few women report their biopsy experience had a negative effect on their lives. In fact, for many women the outcome of the biopsy experience was just the reverse; it provided the impetus for greater awareness of and action about breast health. While virtually all women found the experience upsetting initially, they tend to come through the experience unfazed.

Despite the advent of new biopsy devices, it appears that physicians still rely on traditional surgery. Eight in 10 women surveyed report their biopsy was conducted via open surgery, while just 18% underwent one of the newer procedures such as a Mammotome, Tru-Cut, or ABBI (Advanced Breast Biopsy Instrumentation). As a result, few women (31 %) are being told about these minimally invasive biopsy options, preventing them from making informed healthcare choices.

On the bright side, two-thirds of women overall report their doctor thoroughly discussed the benefits and drawbacks of the procedure they would have, and at least seven in 10 report they were fully informed about various aspects of the procedure, including the amount of time they would have to wait for the results (85%) and the amount of discomfort they were likely to experience (72%).

However, the need for information about biopsies is apparent. One-third of women volunteer that worries about the biopsy itself -- particularly a lack of information and understanding about it - contributed to their fear and stress. Another one-quarter volunteered that gaining access to information is something they would recommend to another woman. Two in 10 report that in retrospect, they would seek more information the next time.

In today's fast-paced health care environment, 55% of women indicate that having more time to spend with their doctor prior to the biopsy would have been helpful. Similarly, another 63% report that feeling comfortable enough to ask the doctor more questions would have been a help to them, indicating some may have felt hesitant and rushed. A majority of women report that having printed material or videos (72%) and being able to speak with another woman who had undergone a biopsy (68%) would have helped them.

## KEY FINDINGS

- More than half of women (56%) report their breast abnormality was discovered through a routine mammogram.
- Eight in 10 women (79%) report having had an open surgical biopsy to characterize their suspicious mass, with the following results: 83% benign, 17% malignant.
- Among all women surveyed, an average of nearly two biopsies (1.86) was reported. More than half of the women (58%) had one biopsy, 26% had two biopsies, and 16% had three or more biopsies.
- Overall, two-thirds of women report their doctor did not discuss different biopsy options with them, indicating that many women may be missing out on choices.
- Among women whose doctor did not discuss any biopsy options, nearly four in 10 report their physician did not thoroughly describe the benefits and drawbacks of the procedure they did have. This represents a rather large group of women who lacked both choice and information.
- On average, women wait nine days before undergoing their biopsy once the need for a biopsy is established. During the waiting period, virtually all women (92%) experience emotions such as fear or stress. However, only a few women report these emotions are disruptive enough to prevent them from carrying out day-to-day activities, thinking clearly, and effectively communicating with their physician.
- Fear of cancer and illness is the most frequently mentioned cause of negative emotions, even though 76% of women had been told there was a greater chance their prognosis would be benign than malignant.
- One-third of women volunteer that not having enough information about the biopsy itself contributes to fear and stress. And when asked to volunteer how they would describe the biopsy to a woman who is facing one, one-quarter mention the need to seek out information.
- However upsetting the biopsy experience may have been at the time, more than half of women indicate that the experience had some positive effects, particularly concerning compliance with good breast health practices. Three in 10 report that going through the experience had a positive effect on their relationship with their husband or "significant other," the person most frequently mentioned when women were asked who they told about the need for biopsy.

- Of the women surveyed, women ages 45 and under (26% of the survey population) are the most pro-active with respect to their breast health - they are more likely to discuss different procedures with their doctors (42% vs. 27%) and, along with women ages 45-64, are more likely to report feeling "fully informed" about specific aspects of the biopsy. These younger women ages 45 and under are also more likely to have found an abnormality during a breast self-examination. However, like most of the women surveyed, the majority of these younger women were not offered alternatives to surgery.
- Between one-half and up to three-quarters of all women report that having had additional information would have been helpful to them. Useful information sources ranged from having more time to spend with the doctor (55%) to having printed materials or videos that describe or illustrate the procedure (72%).