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Needle Localization for Breast Biopsy: The Patient's Experience

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NEEDLE LOCALIZATION FOR BREAST BIOPSY:

THE PATIENT'S EXPERIENCE

by

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ABSTRACT

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The needle localization procedure for breast biopsy (NLP) can be painful and distressing for some women. This study was carried out to learn what factors might increase or decrease NLP pain and distress, and to gain insight into possible interventions to make the procedure more comfortable for all patients. One hundred and thirty-eight women were surveyed following breast needle localization at two central Virginia hospitals. The influence of eight variables (lidocaine, self-regulation, anxiety, worry about breast cancer, breast tenderness, finding mammography painful, difficulty with surgery, and distress of blood drawing) on four outcome variables (pain incidence, pain intensity, pain unpleasantness, and distress) was evaluated. The unpleasantness and intensity of pain proved to be highly correlated and were collapsed into one combined variable, painfulness.

The results suggest that although lidocaine did not eliminate all pain, women who were given lidocaine were less likely to experience pain than those who were not given lidocaine. Although self-regulation did not appear to reduce the incidence of pain, the use of self-regulation strategies, particularly social support, did appear to reduce the intensity and unpleasantness of pain (painfulness) experienced during the breast needle localization procedure. Experiencing pain increased distress, with no statistically significant alleviation of distress from lidocaine or self-regulation. Regression analysis revealed significant relationships between generally finding mammography painful and ratings of NLP

painfulness, and between prior anxiety about the NLP and finding the experience distressing.

These results are discussed in light of their treatment implications. It appears that women undergoing breast needle localization should be given lidocaine, and should be encouraged to practise some form of self-regulation. Patients may especially benefit from the presence of a friend or relative, or the kindness, encouragement, considerate touch, or clear information offered by clinic staff. It may be wise to identify women who generally find mammography painful or who are anxious about the NLP before the procedure for special support.

I dedicate this dissertation with warmest aloha
to two people whose enjoyment of being alive delights and inspires
their fortunate friends and relatives: Al Shapero, who helped me over and around
countless obstacles, and my friend from childhood Cathy Hiebert Kerst.
To them and to the reader, I offer a cinquaine:

All one
afternoon she
measured out the angles
of the world and caught in her web
the wind.

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CHAPTER I

INTRODUCTION

Overview of the Problem

Breast cancer is a disease characterized by rapid growth and spread of abnormal cells which, if not controlled, can result in the individual's death. It may be particularly disturbing to women to contemplate the diagnosis of cancer in the breast, which is a source of life-giving nurturance, a symbol of femininity, and an intimate part of the body. Cancer of the breast is overwhelmingly a disease of women. In 1998, for example, estimated new cases of breast cancer in the United States among men were 1,600, and among women, 178,700 (American Cancer Society, 1998a). Breast cancer is the leading form of cancer diagnosed in women and the leading cause of cancer deaths in women aged 40 to 55 (American Cancer Society, 1997a). Since 1987, only lung cancer deaths have annually exceeded breast cancer deaths among women (American Cancer Society, 1997b). The incidence rate for breast cancer increased from the 1940's to 1980 at an annual rate of about 1%, and then began to increase at a noticeably higher rate, reaching 4% per year for the period from 1982 to1987 (National Cancer Institute, 1998). More recently, this rate has leveled off at about 110 per 100,000 (American Cancer Society, 1998a). However, according to breast cancer specialist and surgeon Linda Sommers, MD (personal communication, April 19, 1999), the incidence rate of breast cancer in American women is "currently accelerating" to about 1 in 8.3 to 8.5. The mortality rate for breast cancer, 27 deaths per 100,000, remained about the same for 50 years (Ferraro, 1993).

The model for this dissertation was the Publication Manual of the American Psychological Association (4th ed.).

In spite of a slight recent decline in the mortality rate for breast cancer, 180,300 new cases of breast cancer, and about 43,900 deaths, were projected to occur in 1998 (American Cancer Society, 1998a).

Breast cancer has become a public phenomenon. It is discussed openly by women concerned about personal risk, and is a focus of attention in the mass media. This has not always been so. Prior to the mid-1980's, women diagnosed with breast cancer had no access to support groups, and often found that open conversation about any cancer, much less breast cancer, was not socially acceptable (Swanson, 1992). Women with the diagnosis often suffered in solitude. But with gradually changing attitudes came an increased awareness of breast cancer, increased willingness to undergo screening mammography, and support for women who faced breast cancer.

In 1974 and 1975, publicity about breast cancer diagnoses in the wives of the President and the Vice President of the U.S. preceded a sudden jump in the incidence rate of breast cancer. A second jump followed the publication of the American Cancer Society's breast cancer detection guidelines in 1980 and the initiation of a Breast Cancer Awareness Campaign. Increasing numbers of women sought mammograms in response to publicity about breast cancer in the 1980's. For example, the percentage of women older than 40 years of age who had had a mammogram rose from 38% in 1987 to 60% in 1990 (National Cancer Institute, 1997a). The steady increases in breast cancer incidence in the 1980's, and a lack of reliable treatment options, led some women to experience a sense of threat and neglect. A New York Times Magazine cover story (Ferraro, 1993) stated that many activists believed that breast cancer had been ignored for decades because it was a woman's disease. More than 180 politically active patient advocacy groups united as the

National Breast Cancer Coalition in 1991. The activism of AIDS patients and their supporters provided a model for breast cancer advocacy groups, with a focus on finding a cure for the disease, instead of simply coping with it (Ferraro, 1993). The Coalition successfully pressed for higher levels of funding for breast cancer research: a $43 million increase in national funds for breast cancer research in its first year of existence, and an additional $300 million more the next year (Ferraro, 1993). The Coalition is gathering signatures on a petition to demand 2.6 billion dollars in federal breast cancer research funds by the year 2000 (National Breast Cancer Coalition, 1998), and given its track record, may succeed.

Breast cancer research has identified some of the risk factors for the disease. The likelihood of breast cancer increases with age. Other risk factors include a personal or family history of the disease, early menarche, late menopause, biopsy-confirmed atypical hyperplasia (excessive cell grouping, usually in the ducts), never having children or having the first live birth at a late age, recent use of oral contraceptives or postmenopausal estrogens, and higher educational and socioeconomic status. The causal role of dietary factors remains unclear (American Cancer Society, 1998a). Despite the identification of risk factors, however, about 45% of the women who are diagnosed with breast cancer have no known risk factors (Martha Jefferson Hospital, 1995). To date, knowledge about risk factors has not led to practical or sure ways to prevent breast cancer, and the best means of reducing mortality is through early detection (American Cancer Society, 1998b).

The earliest sign of breast cancer may be an abnormality that shows up on a mammogram before it can be felt by the woman or her health care provider. Sixty-five percent of women diagnosed with breast cancer survive 10 years, and 56% survive 15

years (American Cancer Society, 1998a). If breast cancer is detected early, survival rates improve. The five year survival rate for localized breast cancer is 97%. For cancer that has spread regionally, the rate is 76%, and for women with distant metastases the rate is 21%. Survival after a diagnosis of breast cancer continues to decline beyond five years (American Cancer Society, 1998a). It is important to discover breast cancer long before the breast shows physical symptoms of the disease: a lump, swelling, thickening, dimpling, skin irritation, distortion, retraction, scaliness, nipple discharge, or tenderness.

Screening mammography raises questions without confirming the malignant or benign nature of a particular area of the breast. If an abnormality is visible, it usually must be further explored through biopsy and examination under a microscope. The precise area of the abnormality must be determined, and a biopsy that neither misses that area nor removes excess normal tissue around it must be undertaken. This is particularly important given that most biopsies yield benign results. Compliance with screening guidelines could result in over a million breast biopsies annually in the United States, and, assuming a malignancy rate of 25%, more than 750,000 biopsies yielding benign results (Evans, 1996). One of the methods to ensure precise biopsies is the needle localization procedure, or NLP. Needle localization, described in detail below, mechanically pinpoints the site of the lesion with a wire introduced into the breast just prior to surgical biopsy. This study explores women's subjective experience of this invasive procedure, and the possible need for interventions to reduce pain and distress.

Screening for Breast Cancer

Although breast x-rays have been performed for more than 70 years, modern mammography began in 1969, the year the first x-ray units dedicated to breast-imaging

were available (American Cancer Society, 1998b). Since then, mammography, or low-dose x-ray examination of the breasts, has become the accepted method of screening for breast cancer (Wilhelm & Wanebo, 1988). Recommendations have varied regarding frequency of mammography for women in different age groups. In December 1993, the National Cancer Institute (NCI) broke ranks with other medical organizations by recommending mammograms every 1 to 2 years only for women over fifty, and none for younger women except those in certain high-risk categories. The NCI pointed to the high cost of expanded screenings, and the much higher rate of negative findings in women under fifty (Papazian, 1994). Thousands of women unlikely to have breast cancer were undergoing biopsies of benign tissue. However, the American Cancer Society continued to promote baseline mammography at age 40, with repeat screenings every 1 to 2 years until age 50, and annual screening after 50 (Kushner, 1995). In March 1997, the National Cancer Institute again recommended annual mammograms for women in their 40's. Scientific experts weighed the evidence "in an emotionally charged atmosphere," with the chief of the National Cancer Institute, Richard D. Klausner, acknowledging "a tremendous amount of pressure from all sides." Klausner commented that "the data are complex and the evidence is not transparent" with different standards of evidence leading different groups to different conclusions (Brown, 1997). The National Cancer Institute and the American Cancer Society agreed to issue a joint statement in March 1997 proclaiming mammography screening of women in their 40's to be "beneficial and supportable with the current scientific evidence" (National Cancer Institute, 1997b). While some organizations like the American College of Physicians and the U.S. Preventive Services Task Force continue to regard the costs of screening mammography for women in their 40's to be too

great for expected benefits, medical organizations are unanimous on the need for mammograms in women 50 and older (Brown, 1997). Public campaigns to encourage breast cancer awareness and mammography, and the expansion of mammographic facilities, have led to increases in breast cancer screening mammography (Wilhelm & Wanebo, 1988). Abnormal mammograms usually lead to further action, including biopsy, to rule out breast cancer.

Breast Biopsies

It is not easy to distinguish benign from malignant breast lesions, even for experienced radiographers (Leinster, Whitehouse, & McDicken, 1987). Most biopsied lesions prove to be benign, with the rate of positive biopsies ranging from 10% to 30% (Leinster et al., 1987), depending on the aggressiveness of the screening program. The University of Virginia's Breast Resource Center reassures its patients that of all women who have an abnormality identified by mammogram, only about 20% have a form of breast cancer (University of Virginia Breast Resource Center, 1996). This means, of course, that about 80% of the women who undergo breast biopsy because of an apparently abnormal mammogram will learn that there was no malignancy in the breast tissue removed.

When a woman undergoing routine mammography is discovered to have a non-palpable lesion, a decision must be made as to whether or not to biopsy the lesion. If the decision is to proceed, the lesion must be pinpointed to locate it for the biopsy. Either samples of the suspicious area are taken, or the lesion is completely removed, along with a minimum amount of the surrounding normal tissue. This is particularly important given that in about 80% of the cases, the excised lesions are benign. There are several options

for pinpointing and removing breast tissue for examination to confirm or rule out the presence of breast cancer. Localization of such lesions for surgery via mammography alone can be difficult, because the position and shape of the breast are altered by vertical and horizontal compression inherent in the mammographic procedure (Frank, Hall, & Steer, 1976).

In the 1960's, early methods developed to localize lesions for surgery included (a) the use of external grids drawn with reference to the mammographic image, (b) placement of a needle within the breast during mammography to serve as a marker, and (c) the injection of methylene blue dye or radiographic contrast material to provide a marker on preoperative locating films (Frank et al., 1976). However, there were drawbacks to each of these methods. Dispersion of dye contrast mediums within the breast, and the merely approximate guidance provided by external grids and location via mathematical triangulation, led to imprecision in surgical biopsy. These inadequate localization procedures could result in the removal of too much healthy tissue surrounding a lesion, or could lead a surgeon to miss the area of concern entirely. In addition, there was a danger of tissue damage during compression mammography, if a sharp needle were inserted and left in place for post-localization films prior to surgery (Frank et al., 1976).

Over time, improved methods of imaging the breast, reading the images, and localizing lesions for biopsy have evolved. Among them are digital mammography, magnetic resonance imaging, digital ultrasound, and computer-aided analysis for clearer images and more precise analysis of those images. For years, excisional surgical biopsy was the only way of securing tissue for a pathologist to examine under the microscope (American Cancer Society, 1998b). The mammogram was used as a guide for placing a

thin wire near the abnormality (breast needle localization), and the area around the wire was removed in the operating room. In the last three or four years, stereotactic core breast biopsy has replaced needle localization in some instances. In this procedure, the patient lies prone on the stereotactic table, with the breast suspended through a hole in the table. The breast is placed in compression and images are taken using digital x-rays. The physician uses a computer to calculate the co-ordinates of the area of suspicion. This information is then transmitted to the needle guidance unit beneath the table which guides the biopsy needle to the exact co-ordinates of the lesion. A large bore needle is used to withdraw 6-10 cores of tissue about 2-3 mm in diameter, or one core of tissue from 5 mm (the size of a pencil tip eraser) to 20 mm (the size of a nickel), removing the entire lesion. These procedures are done under local anesthesia (Hinshaw & Varde, 1998). Evans (1996) reported a concordance range of stereotactic core biopsy and surgical biopsy from 71% to 99% in seven comparison studies carried out in the early 1990's. He also noted that the overall cost for stereotactic biopsy was one third to one fourth that of surgical biopsy. He predicted that the procedure would gain increasing acceptance and needle localizations would decrease. However, some mammographic lesions cannot be biopsied stereotactically. These include areas that are vague on the mammogram, areas of diffuse calcifications, lesions that are close to the chest wall, or lesions in small breasts (Evans, 1996). Needle localization biopsies continue to be widely performed, though as a percentage of all breast biopsies they may be declining as additional procedures are researched and incorporated into the care of women suspected of having breast cancer.

Breast Needle Localization Procedure

The breast needle localization procedure, or NLP, was first introduced in 1976.

This procedure localized the suspicious lesion for surgical biopsy, allowing its removal while removing the least amount of breast tissue (Proudfoot, Mattingly, Stelling, & Fine, 1986). During mammographic compression of the breast in NLP, a hollow needle with a hooked wire inside it is inserted into the breast through a perforated compression plate. Breast compression in the range of 25-40 pounds per square inch (Nielsen, Miaskowski, & Dibble, 1993) may be maintained for 20 to 60 minutes (Schlesinger, Laurito, Baughman, & Carranza, 1989) while placement of the wire within the breast is checked and adjusted. The needle is then withdrawn, leaving the tip of the wire in place, below and ideally within one centimeter of the lesion to pinpoint it for surgical removal. The wire may be bent over at the point of entry into the skin, and stabilized with a small device to help prevent deeper penetration. The hook or barb at the tip of the wire also helps to prevent the wire from pulling out (Wilhelm & Wanebo, 1988). Post-localization films, taken with the woman seated for mammography and requiring her co-operation in response to instructions for positioning herself, confirm that the guide wire is properly placed to locate the lesion for the surgeon. The need for a woman to be able to sit upright and respond to instructions has been one reason for not providing anesthesia that might hamper her ability to do so. Surgical biopsy is then carried out within a few hours of the NLP procedure, under local anesthesia, or, for deep lesions or bilateral biopsies, general anesthesia (Wilhelm & Wanebo, 1988). While waiting for her surgery, the patient copes with any anxiety or discomfort as best she can, with the hooked wire inserted and fixed in place.

Mammography and Pain

The issue of pain during mammography has received little research or clinical

attention (Keefe, Hauck, Egert, Rimer, & Kornguth, 1994), and there is almost no systematic research investigating pain during NLP. One of the largest surveys of asymptomatic women's experience of mammography (Stomper et al.,1988) showed that of 1,847 women screened at seven centers, 39% experienced mild discomfort, 9% experienced moderate discomfort, 1% severe discomfort, and 1% moderate pain. A retrospective study of 985 women reported that 15% of both first-mammogram and repeat mammogram patients found the experience to be "more painful" than they had expected, though this study does not identify women who did expect and did experience moderate to severe pain (Wolosin, 1989). A survey of 356 women (Jackson, Lex, & Smith, 1988) found that 78% reported discomfort ranging from mildly to very uncomfortable, with 3% reporting "intolerable" discomfort. A fourth study found that 4.5% of women found mammography to be painful or very painful, whereas an additional 49% found the procedure to be uncomfortable (Brew, Billings, & Chisholm, 1989). Nielsen et al. (1993) report that, overall, investigators in these studies concluded that "pain was not a major problem for women receiving mammography screening even though a significant number of women in each study reported that they had experienced pain." They point to more recent studies in which pain, discomfort, and anxiety were measured, and 47% to 70% of respondents reported experiencing pain or discomfort (Nielsen, Miaskowski, Dibble, Beber, Altman, & McCoy, 1991). In these studies, increased levels of anxiety were associated with significantly more pain and discomfort. They assert that pain and discomfort are a problem for women undergoing screening mammography, and that women's reactions are significant because a screening procedure must be acceptable to the population for which it is intended. These reported reactions of

anxiety, discomfort, and pain occur during breast compression lasting a few seconds, in asymptomatic women undergoing screening mammography. The same concerns about anxiety, discomfort, and pain are at least equally relevant to and important in the needle localization procedure, which involves prolonged breast compression and the insertion of a needle and wire into the breast of a woman who has been told her mammogram was abnormal.

Needle Localization Procedure and Pain

NLP involves not only prolonged mammographic compression but the simultaneous insertion of a needle and placement of a wire in a highly sensitive area under highly anxiety-provoking circumstances. It is reasonable to suppose that (a) the prolongation of breast compression, (b) the insertion of a needle into the breast, (c) the prolonged presence of a hooked wire in the breast, (d) anticipation of imminent surgery, and (e) knowledge that the breast contains a lesion that may be diagnosed as malignant, and may lead to mortal illness, might combine to increase dramatically the levels of discomfort and pain in women undergoing needle localization. Christine Saul, RN, is Women's Care Liaison at the Martha Jefferson Hospital Breast Clinic and follows every patient undergoing NLP there. She observes that the NLP and surgical biopsy are "much more than a diagnostic and surgical procedure" (personal communication, May 6, 1999). She reported that in her experience some patients "are more on edge and have more pain because of their fears" and some women begin to worry about insurance coverage for cancer care before they even have a diagnosis.

Greater knowledge about the patient's experience of discomfort and pain during NLP might stimulate shifts in research and standards of practice if pain levels were

deemed to be unacceptable. A search of the literature turned up very few articles reporting research specifically on pain associated with NLP. Schlesinger et al. (1989) discussed the use of interpleural bupivacaine for local anesthesia and pain management during NLP and subsequent biopsy in three patients. At the time of publication, this was a new technique for the management of chest wall and upper abdominal pain. It was successful in providing a complete anesthetic for both NLP and the surgical biopsy carried out two to three hours later. Schlesinger et al. observed that no prior study had assessed pain during NLP. Helvie, Ikeda, and Adler (1991) noted "extreme pain" in 1% of patients undergoing NLP. In addition, 7% of patients were reported to experience vasovagal reactions, from light-headedness to syncope, or fainting. The use of local anesthesia did not affect the frequency of vasovagal reactions. The authors pointed out that "anxiety and anticipation," in addition to pain and discomfort, play a role in vasovagal reactions, and suggested studying the efficacy of premedicating patients with anxiolytic medications. They also recommended simply monitoring patients for signs of light-headedness, and ensuring that such patients have a place to lie down.

Reynolds, Jackson, and Musick (1993) evaluated the use of non-buffered lidocaine during NLP. Patients receiving this intervention had a slightly higher mean pain score than those who did not. The authors speculated that the use of non-buffered lidocaine, which stings while it is being infiltrated, may have led to higher overall pain. They also speculated that administering local anesthesia may suggest to the patient an expectation that the procedure will be painful. There appear to be no comparative studies of the use of a sedative, or of buffered lidocaine, or of techniques of infiltrating non-buffered lidocaine which could reduce the stinging sensation. Buffered lidocaine has the advantage

of not stinging, but it is unstable, and requires preparation close to the time of use and careful storage. One article by Gisvold and Martin (1984) mentions adverse patient reactions to NLP, although it does not study them. The authors reported that the most common problem during NLP was "vasovagal reactions, sometimes with actual syncope." In other words, some women fainted from pain or anxiety or a combination of the two associated with NLP, a problem for which the authors simply suggest having a cot in the mammography suite to allow patients to rest. The authors comment, "...this problem can significantly delay completion of the procedure." However, there is no exploration of why patients might feel faint or lose consciousness during the procedure. Nor is there any suggestion for preventing such reactions.

Physicians anonymously reviewing a 1993 grant application at the University of Virginia to study pain and possible interventions during NLP note the same phenomenon of syncope during NLP and unconcern about it as a significant difficulty (University of Virginia, 1993). One reviewer observed "This is a common procedure (performed about 350/year) and is obviously an anxiety-provoking procedure for many patients. It is not uncommon for women to faint during these procedures. This may be related to pain, anxiety, or both. No form of sedation or anesthesia is generally used." A second reviewer comments "An informal survey of clinicians involved in the management of breast carcinoma and NLP did not reveal a concern, at least from the clinician's standpoint, that this procedure itself presents significant difficulties in terms of patient acceptability or coping."

There are several possible reasons for the paucity of research on pain during needle localization for breast biopsy. One theory is that many physicians consider the

procedure uncomfortable but well-tolerated in most women (Reynolds, Jackson, & Musick, 1993). Another possibility is that however uncomfortable or painful the procedure may be, patients cannot be given anything that might prevent them from remaining alert and co-operative for post-placement radiographic films that confirm that the wire has been accurately placed. A third explanation is that pain during NLP may seem unimportant in the context of the possible diagnosis of breast cancer. Finally, a fourth theory is that disregard of the painfulness of NLP relates to a historical sociocultural tendency to minimize pain reports by women, and to undertreat women's pain (Morris, 1991; Caton, 1999).

On the basis of anecdotal reports and a pilot survey of eleven women which I conducted in late 1993 and early 1994, there was evidence that some women do find the NLP experience very painful (see Appendix E). One respondent wrote "The pain was extremely intense.... There seemed to be this 'surprise' that it could possibly be painful." She added "In the future, I would avoid this procedure if at all possible." A second respondent wrote "the wire had to be moved several times within my breast while I was squeezed between mammographic plates. The pain was quite terrible." This respondent said she was "incredulous that women would be subjected to such a painful dehumanizing procedure in this day and age." A third respondent commented "I experienced quite a bit of pain, but realized the procedure was necessary, so I clenched my teeth and bore the discomfort." A fourth respondent wrote that because of her anxiety regarding potential breast cancer, she was "less relaxed therefore more apprehensive about [the] procedure, [and] this increased [the] pain level." Two other women wrote of fainting or "almost" fainting during NLP. These comments indicated that at least some percentage of the

women undergoing NLP find the experience painful.

Following this pilot survey, it remained to be explored through systematic research sampling how many women undergoing NLP found it painful, how intense or unpleasant the pain was felt to be, how distressing the NLP was regardless of pain, and what factors might be associated with these variables.

Factors Associated With Pain

Women undergoing NLP may anticipate and be anxious about discomfort or pain, possible physical damage, and the potential diagnosis of cancer. High levels of anxiety during the NLP can lead to complications during the procedure (e.g., higher perceived level of pain or longer duration of the procedure) and during recovery (e.g., fatigue, emotional distress, and pain) (Weller & Hener, 1993). The high degree of invasiveness of the procedure (both in exposure and compression of the breast and in the insertion of a needle and wire) is likely to increase anxiety (Weller & Hener, 1993) and lower defenses in the face of pain. Pain is never merely a physical sensation, but exists only as we perceive and interpret it (Morris, 1991). It is a multidimensional experience, subjective and complex, related for example to past experiences, the meaning of the situation, and arousal levels (Turk & Melzack, 1992). In 1979, the Subcommittee on Taxonomy of the International Association for the Study of Pain defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage" (Hamill & Rowlingson, 1994). Any study of a possibly painful procedure must consider what factors may influence the sensory and emotional experience of that procedure, and select from many such variables those likely to be significant.

The sensitivity of breast tissue varies from one individual to another, and in the

same individual during her menstrual cycle (Keefe et al., 1994). A woman who undergoes NLP in the week before the start of her menstrual period may experience increased breast tenderness and discomfort during mammographic compression. It is reasonable to ascertain the menstrual status of an individual undergoing NLP, and to ask if she was experiencing breast tenderness before coming in for the NLP that day, whatever her menstrual status. In addition, those who consider mammography a painful experience are likely to report a higher level of pain (Reynolds et al., 1993), so the survey asks if the woman generally finds mammography to be painful procedure.

Research also has supported the possibility that caffeine consumption may be associated with increased breast tenderness (Jackson et al., 1988). Thus, it is also reasonable to inquire about caffeine intake at the time of the NLP. In addition, a difficult previous experience with surgery may lead an individual to be anxious about the surgical biopsy that will promptly follow NLP, aggravating pain perception during the procedure. Similarly, some people have a strong aversion to needles, and this too could influence the painfulness of NLP.

It is important to ascertain the level of anxiety that an individual reports having felt before the needle localization. Keefe et al. (1994) state that negative emotional arousal is an important variable affecting report of pain. They add that a powerful source of anxiety during mammography is the fear of cancer, particularly in women undergoing diagnostic mammography. The survey queries patients about their level of anxiety before the procedure, and degree of worry about a possible diagnosis of breast cancer. It is always possible that an individual undergoing needle localization has taken or been given medication in advance of the procedure that might attenuate the experience of anxiety and

pain. This may include an anxiolytic like xanax. It is also possible that the individual will attempt to cope with the procedure through some form of self-regulation, perhaps focusing on breathing, counting specks on the wall, recalling a pleasant event, and so forth. The variable use of these coping strategies may influence levels of pain experienced during the NLP.

If the experience of NLP is sufficiently aversive, some women may withdraw from diagnostic efforts despite the discovery of new lesions. In addition, an aversive experience of NLP may undermine a woman's ability to cope with surgery or with a diagnosis of breast cancer, should one be made. If the subset of women likely to find NLP painful can be identified, and either pharmacological or non-pharmacological interventions to alleviate anxiety and pain can be offered, this will help these women to muster their own internal resources and remain engaged in a critically important diagnostic effort.

The current study focuses on women's experience of needle localization for breast biopsy, and evaluates the influence of various factors on their experience of the procedure for possible predictive value. The study specifically considers whether or not women experience pain during NLP, the intensity and unpleasantness of any reported pain, and the degree to which women find the NLP distressing regardless of experiencing pain. Variables evaluated are the level of anxiety before the NLP, the degree of worry about a possible diagnosis of breast cancer, and medication taken or self-regulation methods used by patients during the procedure. Additional variables evaluated include menstrual status and breast tenderness on the day of the NLP, considering mammography painful, use of caffeine, and prior experience of surgery and having blood drawn. Discursive comments

provided in response to open-ended questions about (a) actions taken by the patient to make the NLP more comfortable or tolerable, (b) her physical and emotional reactions to the experience of NLP, and (c) what she would like doctors to know about her experience in order to make NLP as comfortable as possible for other patients constitute a rich source of information about the procedure. Little attention has been given to the subjective experience women have of needle localization. The analysis of data gathered from 1994 through mid-1996 makes this in effect an archival research study, though one that is highly relevant to current diagnostic practices and useful in assessing those practices and their impact on women. I hope that the information gathered will help to determine the possible need for interventions to ease anxiety and alleviate pain, if any, in women undergoing needle localization and perhaps other diagnostic procedures when breast cancer is suspected.

Hypotheses

This was a largely descriptive study, with an expectation of determining independent variables that are (a) predictive of pain levels (how intense and unpleasant the pain is), and (b) predictive of experiencing the NLP as upsetting or distressing regardless of pain. Based upon the existing literature in the field of diagnostic procedures for breast cancer including mammography and the patient's experience, and the fields of pain management and pain psychology, the following hypotheses were offered.

Hypothesis 1. Women given lidocaine would have lower levels of pain incidence, pain intensity and unpleasantness, and distress than would women who were given no medication.

Hypothesis 2. Women given lidocaine also would be more likely to report use of

a self-regulation strategy than would women who were given no medication.

Hypothesis 3. Use of a self-regulation strategy would be correlated with lower levels of pain incidence, pain intensity and unpleasantness, and distress, and the use of social support would be the most effective of the self-regulation strategies.

Hypothesis 4. Women who reported a higher level of prior anxiety about the NLP or a higher level of worry about a possible diagnosis of breast cancer also would report a higher incidence of pain, higher levels of pain intensity and unpleasantness, and a higher level of distress.

Hypothesis 5. Women who reported a higher level of breast tenderness on the day of the NLP or a higher level of generally finding mammography painful also would report a higher incidence of pain, higher levels of pain intensity and unpleasantness, and a higher level of distress.

Hypothesis 6. Women who reported higher levels of difficulty with prior surgery or who reported higher levels of distress during prior blood drawing also would report a higher incidence of pain, higher levels of pain intensity and unpleasantness, and a higher level of distress, although the NLP and blood drawing are qualitatively different experiences.

CHAPTER II

METHOD

Subjects

Potential subjects for this study were women aged 18 or above, able to read and comprehend the survey instrument, who were undergoing breast needle localization at one of two Charlottesville, Virginia hospitals following an abnormal mammogram. Given that the study involved only interviews and surveys, and no interventions with patients, a waiver of formal review was granted by the University of Virginia Human Investigation Committee. When permission was later sought to conduct interviews at Martha Jefferson Hospital, formal review was again waived.

Data were gathered from 58 NLP patients in face-to-face interviews immediately following the procedure (30 women at the University of Virginia Health Sciences Center, 28 women at Martha Jefferson Hospital) and from 80 retrospective surveys mailed to NLP patients previously seen at the University of Virginia, for a total of 138 women who provided information about their experience of breast needle localization. The NLPs in question took place during a two and a half year period, from January 1994 through February 1996 at the Diagnostic Center for Women (DCW) of the University of Virginia Health Sciences Center, and August 1995 through June 1996 at the Outpatient Surgery Clinic (OSC) at Martha Jefferson Hospital. The data were gathered under the auspices of the Pain Management Center of the University of Virginia Department of Anesthesiology, and the two hospital-based clinics listed above. Needle localization procedure patients were told that information gathered would be confidential, and would be useful in exploring women's subjective experience of guide wire insertion (the term used in the

survey) and the need for interventions to make the procedure as comfortable as possible for all patients. The women were asked to give their age, their ethnicity, their education or highest level of school completed (with a choice of seven categories), and their household income (five categories). The patients who provided information ranged in age from 25 to 90 years, with a mean age of 55.6 years. Of the sample of 138 women, 18 were African-American, 1 was Asian-American, 116 were European-American, and 3 did not identify their ethnicity. All 138 women answered a question on level of education, as shown in Table 1.

Table 1

Highest Level of Education Completed

Less than 8th grade	11	Completed college	28
Completed 8th grade	7	Technical or Business School	10
Completed high school	39	Graduate or Professional Degree	28
Some college	15	Total	138

When asked about annual household income from all sources, twenty-one women reported "less than $10,000," seventeen women reported their annual household income to be $10,000 to $20,000, thirty-six women answered $20,000 to $40,000, twenty answered $40,000 to $60,000, and thirty-five women reported an annual household income over $60,000. Information on annual household income was missing for nine women.

Materials

This study relies on data gathered in response to two survey forms. The concurrent form (see Appendix A) was developed for face-to-face interviews conducted immediately following the NLP while women were waiting for surgical biopsy. A slightly modified version, the retrospective form (see Appendix B), was mailed to and completed by women after they had already experienced the breast needle localization procedure and surgical biopsy.

The original pilot survey form (Appendix E) was generated following a review of the literature and discussions with Rebecca Lewis, RN, and Joe Dane, PhD, clinical pain psychologist, both at the University of Virginia Health Sciences Center. The pilot survey asked for basic demographic data: age, level of education, ethnicity, and household income. Respondents were asked to rate the level of pain they experienced, and to rate their level of distress. They also were asked about anxiety prior to the NLP. They were given a chance to comment on their physical and emotional reaction to the NLP, and asked what they would want doctors to know about their experience in order to make the procedure as comfortable as possible for patients. Other variables assessed in the pilot survey were prior difficulty with surgery, caffeine consumption, and perception of mammography as a painful procedure.

The three-page survey instrument for use in concurrent interviews (Appendix A) asked for both numerical ratings and comparisons and for subjective commentary on the experience, as well as for demographic data. Women were asked if they had experienced pain during the NLP. This was followed by four questions asking the women to rate the intensity and unpleasantness of the pain (if any), to rate how distressing they found the

NLP, and to rate their level of prior anxiety. These questions were accompanied by a ten point horizontal scale, as illustrated in Figure 1.

Q8. Please rate your level of anxiety about the guide wire insertion *before* having it done:

Not at all anxious 1 2 3 4 5 6 7 8 9 10 Most anxious imaginable

Figure 1. Example of Question With Horizontal Response Scale

Five questions (17-21) focus on menstrual status, breast tenderness, and whether or not the respondent generally found mammography a painful procedure.

The survey specifically queries patients about level of anxiety before the procedure, and degree of worry about a possible diagnosis of breast cancer. Patients are also asked about prior difficult or painful experiences associated with surgery or with needles (questions 23-27), with the assumption that these past experiences may lead to negative emotional arousal in anticipation of the NLP and subsequent surgery, and to higher levels of reported pain. The survey asks if any medication was given to or taken by the woman to make her more comfortable during NLP, as this certainly might affect the level of pain experienced and reported. An additional question focuses on self-regulation strategies that may have been used by the patient to reduce pain and discomfort. Talking with the technician, rational appraisal, prayer, relaxation, or holding a nurse's hand are some of the strategies described in response to the question. Responses were coded in two categories, social support and other forms of self-regulation. The survey asked respondents if they experienced pain during the guide wire insertion, and also how intense and how unpleasant or disturbing the pain was perceived to be. In addition, regardless of

whether or not respondents experienced pain, they were asked to report the degree to which the guide wire insertion was experienced as upsetting or distressing. Patients were also given opportunities to comment in response to open-ended questions.

Procedure

A pilot survey (see Appendix E) was mailed in December 1993 to eleven women who had undergone breast needle localization at the University of Virginia Health Sciences Center. These women were friends, acquaintances, or friends of friends of a University of Virginia nursing administrator knowledgeable about and interested in a study of NLP. Each of the women gave permission to be contacted for the pilot study. Respondents were asked to answer questions both about their experience of NLP and questions about the form itself. They were asked if the survey form was respectful, if any question was unclear, how long it took to complete the form, and if there were other questions we should ask.

In response to the first letter or a follow-up note, nine survey forms were returned. The nine respondents provided useful commentary as well as responses to the questions. The data gathered in this pilot study confirmed that some women find NLP quite painful, suggesting the merit of further research.

In consultation with Joe Dane, PhD, a clinical pain psychologist at the University of Virginia Pain Management Center, and Jennifer Harvey, MD, a radiologist at the Diagnostic Center for Women interested in researching women's experience of NLP, the pilot survey was revised over the following months and readied for use as a survey form (see Appendix A) to be administered in face-to-face interviews at the Diagnostic Center for Women. Interviews were to take place immediately following the needle localization

procedure and prior to surgical biopsy, while women were waiting between the two procedures in a small private waiting room at the Diagnostic Center.

The women were assured of confidentiality and given an opportunity to ask any questions before consenting to be interviewed. They were invited to participate or freely decline to be interviewed. Two women did decline; one seemed agitated and the other preferred to read a magazine while she waited for surgery. However, the Diagnostic Center for Women staff were instructed by Dr. Harvey to include the post-NLP survey as a routine part of the patients' visit to the Center. The survey took approximately twenty minutes. As interviewer, I was present throughout the time it took each patient to complete the survey form, in order to answer any questions and to encourage its completion. Some patients asked me to read the questions to them, saying they did not have their glasses. I recorded their responses verbatim on the form in such cases. Patients were interviewed immediately following the unusual and possibly uncomfortable experience of NLP, while they were waiting to be summoned for imminent surgical biopsy. Some appeared to be feeling emotionally vulnerable. Care was taken to respond with clarity and kindness to concerns they expressed, and many seemed to appreciate being asked about their experience of NLP.

In 1994 the Diagnostic Center for Women was in a transitional period of more frequently offering stereotactic core biopsies in lieu of needle localization and surgical biopsy of breast lesions, as University of Virginia radiologists and oncologists gained increasing confidence in the newer procedure. The number of NLPs performed dropped from about 25 to 30 per month to perhaps 4 to 8 per month. In January 1994, for example, 23 NLPs were carried out at the Diagnostic Center for Women. By the end of

that year in December only 4 NLPs were done. In addition, surgeries began to be scheduled closer to the time of needle localizations. Sometimes a patient was sent up immediately following NLP, with no time for an interview. Other times I would begin an interview only to learn that the surgical suite was calling urgently for the patient. It was costly for the hospital to have the surgical suite be idle, and generally better for the patient not to have a long wait between NLP and surgery. Surgery obviously took precedence over completion of the survey.

Shared concern about the numbers of NLP patients available to be interviewed led Dr. Harvey to contact Martha Jefferson Hospital on my behalf, and I arranged to interview NLP patients at the Outpatient Surgery Clinic there beginning in August 1995. Martha Jefferson Hospital carried out stereotactic core biopsies less frequently than the University of Virginia at that time, sharing a mobile unit with several other hospitals. The staff at Martha Jefferson performing NLPs also were interested in their patients' experience of the procedure, and supportive of the study. The same procedures were followed at both hospitals.

Women were interviewed immediately following NLP and prior to surgical biopsy, in private waiting rooms. They were assured of confidentiality and offered an opportunity to ask questions before consenting to be interviewed. They were invited to participate or freely decline to be interviewed. Two women declined, one because she wanted to spend the time with family who had accompanied her, another because she was too upset, according to the clinic nurses. As was true at the University of Virginia Diagnostic Center for Women, not infrequently a prompt summons for surgery interrupted or prevented an interview. In the end, 58 valid interviews of NLP patients were carried out at the two

hospitals, 30 at the University of Virginia Health Sciences Center and 28 at Martha Jefferson Hospital.

In an effort to increase the sample size of women surveyed regarding their experience of NLP, a parallel retrospective survey (see Appendix B) was mailed in May 1995 with a cover letter (see Appendix C) under the letterhead of the University of Virginia Pain Management Center to 145 women who had undergone NLP during 1994 at the Diagnostic Center for Women, and who had not been interviewed by me. A stamped envelope with the Pain Management Center return address was enclosed to encourage responses. Ten envelopes were returned unopened, marked deceased, addressee unknown, or forwarding order expired. Sixty-six surveys were returned after the initial mailing, and 15 additional surveys were returned in response to a follow-up letter (Appendix D), for a total of 81 retrospective surveys. One was discarded as invalid after Diagnostic Center for Women charts were double-checked and that individual was determined to be answering questions about a stereotactic core biopsy instead of an earlier needle localization procedure. In summary, the data to be analyzed comprised 58 concurrent and 80 retrospective surveys.

CHAPTER III

RESULTS

Initial Results

One hundred and forty-five retrospective surveys were mailed to women who had undergone a breast needle localization procedure at the University of Virginia Diagnostic Center for Women. Sixty-six questionnaires were completed and returned in response to the first mailing. A follow-up letter resulted in an additional 15 completed and returned surveys. Ten of the survey envelopes were returned unopened, marked either deceased, addressee unknown, or forwarding order expired. The return of 81 out of a possible 135 surveys provided a 60% rate of return. One of the eighty-one completed surveys had to be discarded when a check of clinic records showed that the respondent was answering questions on the basis of a stereotactic core biopsy rather than her earlier NLP. Thus, 80 completed retrospective surveys were available for analysis.

The eighty women in this sample were asked if cancer had been diagnosed following their NLP and biopsy. Just over 21% of the women ($n = 17$) answered yes. For 75% of the women ($n = 60$) results were negative. Almost 4% of the women ($n = 3$) chose not to answer this question. Responses to questions on pain were compared for women with breast cancer and women without breast cancer on the assumption that a diagnosis of cancer might affect retrospective reports of pain. No statistically significant differences were found between these two groups of women on retrospective reports of NLP pain.

The concurrent sample of 58 patients was composed of 30 University of Virginia Hospital patients and 28 Martha Jefferson Hospital patients interviewed immediately

following the NLP. Because their responses to key pain questions did not differ statistically, the data from women at the two hospitals were collapsed into one sample.

Next, the retrospective survey sample was compared with the concurrent survey sample (see Table 2). There was no statistically significant difference between these two samples for incidence of pain as determined by a chi-square analysis. There were statistically significant differences between these samples for the unpleasantness and intensity of pain and for NLP distress, though not for anxiety, as determined by t-tests.

Table 2

Means For Pain and Anxiety Questions by Sample

Question	Concurrent sample n = 58	Retrospective sample n = 80	p
Experience pain?	Yes: 57% No: 43%	Yes: 70% No: 30%	n.s.
How intense?	3.6	5.0	.005
How unpleasant?	3.5	5.1	.005
NLP distressing?	2.4	4.8	.0001
Anxiety prior to NLP?	4.5	4.9	n.s.

Note. Respondents circled a number on a scale from 1 to10 for the last four questions.

There were also significant differences between the concurrent and retrospective samples' responses to questions on: (1) medications taken or given, and (2) any

self-regulation methods used in order to make the procedure more comfortable or tolerable. In the concurrent sample, 82.8% of the women reported they had been given or had taken medication "to make [them] more comfortable during the procedure," whereas 15.5% of the women answered no to the question. Approximately 78% of the women in the concurrent sample were given lidocaine, and about 3% of the women were given an anxiolytic. One woman had both lidocaine and an anxiolytic.

In the retrospective sample, only 26% of the women reported they had been given or had taken medication, whereas nearly 68% of the women answered no to the question. Twenty percent of the women in the retrospective sample were given lidocaine, and 3.8% were given an anxiolytic prior to the NLP. Again, one person had both. There were insufficient numbers of women given only an anxiolytic for its effects to be considered as a separate variable in further analyses. Thus, a dichotomous variable, medication / no medication, was established for further analysis.

Whether or not a woman was given lidocaine was up to the attending physician at the University of Virginia Diagnostic Center for Women. Physicians' decisions were based, for example, on their assessment of the patient, the location of the lesion, and their perception of the painfulness of both the NLP and the lidocaine infusion. By contrast, at the Martha Jefferson Hospital Outpatient Surgery Clinic, it was a matter of policy to give every NLP patient lidocaine at the time of the interviews.

All patients were asked "Did you do anything else to make the experience more comfortable or tolerable (for example, distract yourself by concentrating on pleasant thoughts)?" This question sought to identify self-regulation strategies that patients may have employed at the time of the procedure. Approximately 74% of the patients in the

concurrent sample described a strategy they had used, whereas about 53% of patients in the retrospective sample described such a strategy.

Patients were asked if they generally found mammography a painful procedure. On a scale of 1 to 10, the concurrent sample had a mean score of 3.8, whereas the retrospective sample had a mean score of 4.5. On questions regarding breast tenderness on the day of the NLP, difficulty with prior surgery, and levels of pain, distress, and anxiety at the time of their most recent experience of having blood drawn, the concurrent and retrospective samples' mean scores differed little. Results for these questions are shown in Table 3.

Table 3

Means For Mammography Pain, Tenderness, Surgery, and Blood Drawing by Sample

Question	Concurrent sample n = 58	Retrospective sample n = 80	p
Mammography generally painful?	3.8	4.5	n.s.
Tenderness at the time of the NLP?	1.9	1.9	n.s.
How difficult was past surgery?	4.4	4.6	n.s.
How painful having blood drawn?	2.3	2.2	n.s.
How distressing having blood drawn?	2.1	2.2	n.s.
How anxious before having blood drawn?	1.8	2.1	n.s

A correlation matrix was calculated for the main dependent variables of the study. A significant correlation was found between ratings for intensity of pain and ratings for the unpleasant or disturbing nature of the pain (see Table 4). The correlation was .94 for the concurrent sample, .93 for the retrospective sample, and close to .94 for the combined sample. These two variables were combined as a composite index of "painfulness," entailing both the intensity and the unpleasantness of the experience of NLP. In contrast, the correlation for ratings of distress with the above composite variable "painfulness" was only .49 in the concurrent sample. The intensity and unpleasantness of pain during NLP may contribute to ratings for "distress," but the variable may reflect additional factors. Examples are a long wait before the NLP, an encounter with a brusque staff member, or concern about infection. In any case, ratings for the variable of distress were not

Table 4

Correlation of Outcome Variables by Sample

	Concurrent Sample			Retrospective Sample		
	Intense	Unpleasant	Distressing	Intense	Unpleasant	Distressing
Intense	—			—		
Unpleasant	.94	—		.93	—	
Distressing	.49	.48	—	.68	.76	—
Intense+Unpleasant (Painfulness)	.98	.99	.49	.98	.98	.73

correlated highly enough with ratings for painfulness across the concurrent, retrospective, and combined samples to consider distress and painfulness one variable.

Patients' descriptions of strategies they had used to make the experience of NLP more comfortable or tolerable were examined, and several forms of self-regulation emerged. In the concurrent sample, 43 (74%) of the women answered yes when asked if they did something to make the experience more comfortable or tolerable, whereas 15 (26%) answered no. In the retrospective sample, about 42 (53%) of the sample answered yes to this question, whereas approximately 37 (46%) of the sample answered no. The largest number of positive responses (47) fell into a category of self-regulation that could be called social support. Patient responses were coded in this category if they mentioned: 1) helpful clinic staff (e.g., kind, humorous, encouraging, or informative); 2) the presence and support of family or friends; or 3) physical contact with another during the procedure. The following excerpts from Appendix F illustrate the above criteria for coding a form of self-regulation as social support.

"If people are kind to you and joke with you a little bit and call you darling it helps."

"...The technicians told me, in detail, everything they were doing. They were very calm and matter-of-fact. All of the above contributed to my comfort."

"The lady who came over and held my hand was wonderful. I was so scared I had my head turned away, and that meant the world to me. When the lady came around to be with me as a friend that helped me more than anything."

"[My] husband was in there quite a bit. If you do have a loved one with you it helps a whole lot. The lady who was in there was really nice; glad she didn't say no he can't come in."

"Brought my law partner with me as moral support, asked lots of questions."

"The doctors and nurses knew, or guessed accurately, what I was feeling and sought to comfort me. They informed me every moment what they were seeking to do. This meant the most to me and was very calming."

There was relatively good interrater agreement in decisions on whether a strategy was used and if it involved social support. Two raters independently categorized each patient in the concurrent sample and agreed on 93% of the strategies (Cohen's kappa = .89). Discussion of disagreements resolved differences in criteria. Twenty-nine responses in the concurrent sample were coded as Social Support, and the remaining responses were coded variously and grouped as Other self-regulation. These criteria were then used to categorize each patient in the retrospective sample. In summary, of the 85 women in the combined sample who reported using a strategy of some kind, 76 provided a description. Forty-seven of these responses were coded in the category of social support, and 29 were coded as "other self-regulation." The category of social support was singled out as a separate independent variable for further analyses both because it was the largest category of self-regulation found in responses and also because it was the kind of strategy perhaps most readily ensured and encouraged by hospital staff.

Quantitative Analyses

Analyses were carried out to determine the influence of variables hypothesized to significantly reduce pain incidence, pain intensity or unpleasantness, and distress. These variables were use of lidocaine and use of some form of self-regulation. Analyses were also carried out to determine the influence of variables hypothesized to increase or aggravate pain incidence, pain intensity or unpleasantness, and distress. These variables included prior anxiety about the NLP, worry about a diagnosis of breast cancer, breast

tenderness, generally finding mammography painful, and previous difficulty with surgery or with having blood drawn.

It was hypothesized that those who were given lidocaine or who used a form of self-regulation would have lower levels of pain incidence, pain intensity or unpleasantness, and distress. With regard to the incidence of pain, there were no statistically significant effects for use of self-regulation in reducing the incidence of pain. However, medication was associated with a reduced incidence of pain. Table 5 shows the results obtained for the combined (concurrent + retrospective) sample, X^2 (1, N = 132) = 8.22, p < .05. Note

Table 5

Use of Lidocaine and Incidence of Pain, Combined Sample

		Medication Taken?		
		No	Yes	Total
Did you experience pain?				
	No	15 (10.9)	30 (21.7)	45 (35.5)
	Yes	48 (34.8)	39 (28.3)	87 (64.5)
	Total	63 (45.7)	69 (50.0)	

Note. Six of the women's responses (4%) are missing.

that women who reported no medication were three times more likely to experience pain than women who reported being given medication. However, it appears that among women who were given lidocaine pain was not necessarily relieved. An important caveat

is that the proportions given medication in the concurrent sample (82.8%) and in the retrospective sample (67.5%) were different, as were their reports of experiencing pain, with the retrospective sample reporting a greater incidence of pain (70%, vs. 56.9% for the concurrent sample). Given these differences, the same analysis was carried out with the concurrent sample alone, because their recall of the experience was more immediate. Table 6 shows that the pattern of results is essentially the same, although there were too few women in the category of those who did not take medication for the results of this analysis to achieve statistical significance, X^2 (1, N = 57) = 1.68, p > .05.

Table 6

Use of Lidocaine and Incidence of Pain, Concurrent Sample

	Medication Taken?		
	No	Yes	Total
Did you experience pain?			
No	3 (5.2%)	21 (36.2%)	24 (41.4%)
Yes	6 (10.3%)	27 (46.6%)	33 (56.9%)
Total	9 (15.5%)	48 (82.8%)	57 (98.3%)

Note. One woman's response (1.7%) is missing.

It was hypothesized that women who were given medication would be more likely to report a strategy of self-regulation than those women who were not given medication

This prediction rested on the speculation that women given pain medication were alerted to the need to prepare themselves for the procedure, to draw on inner resources or strategies to make the experience of NLP more tolerable or comfortable. A chi-square analysis of the combined sample (N=132) showed that women who reported being given medication were significantly more likely to report use of some form of self-regulation, $X^2(1, N = 132) = 35.27, p < .001$). See Table 7.

Table 7

Medication and Use of Self-Regulation Strategy, Combined Sample

	Medication		
Strategy Use	No	Yes	Totals
No	31 (22.5%)	20 (14.5%)	51 (37%)
Yes	32 (23.2%)	49 (34.5%)	81 (57.7%)
Totals	63 (45.7%)	69 (49%)	132 (94.7%)

Note. Data missing for 6 patients.

Besides reporting whether or not they experienced pain, the women also rated how intense and how unpleasant it was. These responses were combined as an index of "painfulness" in a 3 x 2 analysis of variance (ANOVA) to determine the influence of strategy (social support, any other self-regulation strategy, or no use of self-regulation) and medication (medication taken, no medication taken) in alleviating painfulness. The ANOVA revealed a main effect (delta = .72) for strategy use, $F(2, 80) = 3.49, p < .05$,

but no statistically significant effect for medication, F (1, 80) = 2.20, $p > .05$. On average, women who reported using some form of self-regulation rather than no self-regulation strategy also reported lower levels of painfulness, and those who said they used a strategy of social support reported the lowest level of painfulness, irrespective of having any medication (see Table 8).

Table 8

Means for Painfulness as a Function of Medication by Self-Regulation, Combined Sample

	Medication		
Self-regulation Strategy	No	Yes	Row Means
None	5.80	4.94	5.37
Other than Social Support	4.83	3.71	4.27
Social Support	3.95	3.46	3.71
Column Means	4.86	4.04	

Table 8 shows that the mean levels of painfulness decrease across the different levels of self-regulation whether or not medication was given. Note that the mean levels of painfulness also decrease laterally, with mean levels of painfulness lower for those who were given medication whether or not a form of self-regulation was used. This pattern, however, was not statistically significant. Follow-up Tukey's tests revealed that the difference between the highest and lowest means within strategy (social support versus none) was significant ($p < .01$).

The same analyses of variance for the concurrent and retrospective samples considered separately eliminated the statistical significance of the results, but not the pattern. The same ordering of means from highest to lowest levels of painfulness emerged in considering first patients who reported no use of a self-regulation strategy, then those who used a strategy other than social support, and finally those who used a strategy of social support. This pattern was suggested in the analysis of variance for the 32 member concurrent sample; however, the 32 individuals did not fall evenly into the three categories of self-regulation, so the group means based on small numbers of patients are unreliable. The pattern in the analysis of variance for the 55 member retrospective sample was also the same, with marginally statistically significant results for use of self-regulation strategy ($p = .055$).

In addition to rating the painfulness of the procedure, the women rated how distressing they found the procedure. Ratings of distress were not well correlated with those for painfulness ($r = .49$) and were therefore treated separately as dealing with aspects of the experience beyond only its painfulness. As for the influence of medication and strategy use on these ratings of distress, there were no statistically significant effects (for strategy: $F(2, 80) = 1.82$, $p > .05$; for medication: $F(1, 80) = 2.06$, $p > .05$). However, the same pattern is clear, as shown in Table 9. The means for distress are highest for women who report no strategy of self-regulation, lower for women describing use of a strategy other than social support, and lowest for women describing a strategy of social support. This pattern holds whether or not a patient was given medication.

In sum, experiencing pain during NLP increases ratings for distress, without statistically significant alleviation of distress from medication or self-regulation.

However, self-regulation strategies do appear to have a statistically significant effect in reducing the rated painfulness of the procedure if pain is experienced. Medication also may alleviate painfulness, although, again, its effect was not statistically significant.

Table 9

Means for Distress as a Function of Medication by Self-Regulation, Combined Sample

	Medication		
Self-Regulation	No	Yes	Row Means
None	5.83	5.22	5.52
Other than Social Support	5.07	4.29	4.68
Social Support	4.80	3.09	3.95
Column Means	5.23	4.20	

A second set of hypotheses concerned those variables that might contribute to an increase in the incidence of pain, pain intensity and unpleasantness (combined as the composite variable "painfulness"), and distress. The six variables considered were prior anxiety about the NLP, worry about a possible diagnosis of breast cancer, breast tenderness, generally finding mammography painful, difficulty with previous surgery, or distress having blood drawn. A logistic regression did not reveal any significant predictors among these variables for incidence of pain. The correlations between the variables and painfulness or distress are shown in Table 10 (concurrent sample) and Table 11 (retrospective sample).

There are several correlations in each sample that appear to be statistically significant. Of these, the correlations measuring .30 or above are particularly worth noting. In the concurrent sample (Table 10) worry about cancer is significantly correlated with painfulness (.45), as is breast tenderness (.32), whereas anxiety is significantly correlated with finding the NLP distressing (.36).

Table 10

Correlation of Painfulness and Distress with Predictor Variables, Concurrent Sample

	Outcome Variables	
Predictor Variables	Painfulness	Distress
Anxiety About NLP	.20	.36*
Worry About Possible Cancer	.45*	.24*
Breast Tenderness	.32*	.25*
Mammography Painful	.19	.06
Difficult Past Surgery	.01	.25*
Distress Having Blood Drawn	-.06	.15

*$p < .05$

In the retrospective sample (Table 11) three variables are shown to have statistically significant correlations above .30 with painfulness: breast tenderness (.42), generally finding mammography painful (.33), and distress having blood drawn (.33). Anxiety has a statistically significant correlation with distress (.53).

Table 11

Correlation of Painfulness and Distress with Predictor Variables, Retrospective Sample

	Outcome Variables	
Predictor Variables	Painfulness	Distress
Anxiety About NLP	.22*	.53*
Worry About Possible Cancer	—	—
Breast Tenderness	.42*	.16
Mammography Painful	.33*	.23*
Difficult Past Surgery	-.01	.26*
Distress Having Blood Drawn	.33*	.15

Note. Patients in this sample knew whether or not they had cancer.

*$p < .05$

The separate linear contributions to each of the dependent variables were analyzed using least-squares regressions (see Table 12). In the concurrent sample, no statistically significant linear relationship between the aggravating variables and the ratings of NLP painfulness was revealed, although there was a statistically significant overall relationship between these variables taken together and ratings of distress, $p < .05$. In the retrospective sample, both the regression models were statistically significant overall, $p < .05$, with a statistically significant linear relationship emerging between ratings of NLP painfulness and generally finding mammography painful, and between ratings of distress and rated anxiety prior to the NLP (see Table 12). The linear relationships between these

Table 12

Linear Contributions of Aggravating Variables to Painfulness and Distress by Sample

	Concurrent Sample	
	Model Statistics	
	Adjusted $R^2 = .07$ (n.s.)	Adjusted $R^2 = .25$ $F(6, 41) = 3.6$, $p<.05$
Beta Estimates for Predictors of Rated:	$n = 29$ Painfulness	$n = 48$ Distress
Distress of Blood Drawing	.00	.24
Finding Mammography Painful	.09	-.09
Worry About Cancer	.34	.11
Difficulty with Surgery	-.03	.14
Anxiety about NLP	-.06	.22
Breast Tenderness at time of NLP	.20	.27

	Retrospective Sample	
	Model Statistics	
	Adjusted $R^2 = .26$ $F(5, 37) = 3.93$, $p < .05$	Adjusted $R^2 = .44$ $F(5,53) = 9.95$, $p < .05$
Beta Estimates for Predictors of Rated:	$n = 43$ Painfulness	$n = 59$ Distress
Distress of Blood Drawing	.41	.29
Finding Mammography Painful	.35*	.26
Difficulty with Surgery	-.11	.05
Prior Anxiety	.14	.49**
Breast Tenderness at time of NLP	.11	.14

* $p < .05$; ** $p < .0001$

aggravating variables, taken together, and the ratings of painfulness and distress were somewhat stronger in the retrospective sample than in the concurrent sample, in that the linear models for the retrospective sample were apportioned somewhat more of the overall variance in the responses.

CHAPTER IV

DISCUSSION AND CONCLUSIONS

Overview

The intent of this study was to investigate women's experience of breast needle localization, a procedure designed to pinpoint a possibly malignant lesion in the breast for surgical biopsy and assessment. Of particular interest were the factors that might either aggravate or alleviate pain and distress, with the hope that this information would yield insights into ways of better supporting women undergoing breast needle localization. How is the procedure of needle localization experienced by women? Statistical means for responses to questions provide one answer, but reviewing the range of responses to questions on painfulness and distress is also informative. Most women did report experiencing pain during NLP. Of the 138 women studied, 64% (n = 89) experienced pain. The intensity and unpleasantness of the pain sensation varied for those 89 women. Almost 44% (n = 39) of women who experienced pain reported mild pain intensity of 1 to 3 on a scale of 10, whereas just over 13% (n = 12) reported strong pain intensity of 8 to 10 on a scale of 10. Almost 43% (n = 38) of women who experienced pain reported it to be mildly unpleasant at 1 to 3 on a scale of 10, whereas 16% (n = 14) reported strongly unpleasant pain with scores of 8 to 10 on a scale of 10. Whether or not they experienced pain, the 138 women studied were asked how distressing they found the NLP. Almost 56% (n = 77) found the NLP mildly distressing with scores of 1 to 3 on a scale of 10, whereas almost 17% (n = 23) found it strongly distressing, with scores of 8 to 10 on a scale of 10.

Several hypotheses were proposed to explain this range of responses to the

procedure. First, it was hypothesized that women who were given lidocaine to numb the breast (not a universal practice) would have generally lower ratings for pain and distress. Second, it also was hypothesized that those women given lidocaine would be more likely to report using some form of self-regulation to make the procedure more tolerable or comfortable. Third, it was predicted that use of a self-regulation strategy would reduce pain and distress, and that use of social support would be more effective than other self-regulation strategies. Finally, it was predicted that six variables would aggravate pain and distress in women undergoing the breast needle localization procedure. These six variables were prior anxiety about the NLP, worry about a cancer diagnosis, breast tenderness the day of the NLP, generally finding mammography painful, difficulty with prior surgery, and distress with prior blood drawing.

Major Findings

It appears that NLP patients who receive lidocaine experience less pain, but that lidocaine does not necessarily eliminate pain. Patients who did not receive lidocaine ($n = 63$) were three times more likely to experience pain than not to experience pain. However, patients who were given lidocaine ($n = 69$) were still more likely than not to experience pain. It is possible that the insertion of the needle, the technique of the person conducting the procedure, or the infusion of the lidocaine itself (which results in a burning sensation if not adequately buffered) may cause pain. In some cases the precise area of the breast that needs to be numbed may be missed. The prolonged breast compression required for NLP may be painful and lidocaine is not intended to numb the entire breast. In some cases the NLP procedure may last longer than expected and the effectiveness of the lidocaine may wear off. It also is possible that in some individuals, apprehension (and

pain) may be heightened because of the injection even of a medication intended to relieve pain. Nevertheless, although the injection of lidocaine does not eliminate pain and may even cause some pain, it does appear that women who are given lidocaine are less likely to report experiencing pain than those women who are not given lidocaine, suggesting its value as standard practice. While the technique of lidocaine administration is beyond the purview of this study, variations in preparation, storage, manner of injection, amount given, and choice of area to be numbed, for example, all may influence its effectiveness for each patient. If providing lidocaine becomes standard practice, careful attention must be given to all aspects of its use to maximize the benefits for each woman. In addition, consideration must be given to other kinds of interventions that may help make the NLP procedure more comfortable and tolerable for patients.

It was hypothesized that use of lidocaine would be associated with lower ratings for pain intensity and unpleasantness, and for distress. When the nature of experienced pain (intensity and unpleasantness combined as one variable named "painfulness") was evaluated with regard to medication taken and reported use of self-regulation, an interesting pattern emerged. It appears that if pain is experienced, the use of some form of self-regulation strategy, and especially social support, significantly reduces the intensity and unpleasantness of that pain. Women were assigned to three groups according to their use of self-regulation: no use of self-regulation, something other than social support, and a strategy of social support. On average, women who reported no use of self-regulation reported the highest level of painfulness, women reporting something other than social support reported lower levels of painfulness, and women who described using a social support strategy reported the lowest level of painfulness. This pattern held true

irrespective of having medication. This pattern persisted in separate analyses of the combined, retrospective, and concurrent samples, although with the reduced numbers in the retrospective and concurrent samples, statistical significance was lost. In addition to self-regulation, medication also may have an effect in reducing painfulness. This finding should be interpreted with caution, as traditional levels of statistical significance were not found. Nevertheless, the means for painfulness were lower in magnitude when medication was given than when it was not.

When the influence of self-regulation strategy and medication on a patient's experience of distress was evaluated the same pattern was revealed. Again, the means for distress are highest in the group reporting no self-regulation, lower in the group reporting something other than social support, and lowest in the group reporting social support. Again, medication also may have an effect in reducing distress. Although these results were not statistically significant, this pattern is of interest, and suggests that medication and self-regulation (especially social support) may reduce painfulness and lessen distress. It is possible that with a larger sample the results would achieve statistical significance.

Eighty-five (almost 62%) of the NLP patients described something they were aware of, apart from medication, that helped make the NLP experience more tolerable or comfortable. Some patients deliberately employed a strategy with that intention; others simply recalled and described something that made them feel better. The largest number of the responses dealt with some form of social support. A woman who goes into the hospital for an NLP, in the context of imminent surgical biopsy and a possible cancer diagnosis, may feel very alone. Experiencing pain may increase her feeling of isolation. The interactions she has with others can serve to ease her sense of isolation and reinforce

her ability to cope. Sensitive support of the patient, reflected in kindness, encouragement, humor, adequate information, or considerate physical touch, may alleviate experienced pain and distress. Support of the NLP patient can be offered both by clinic staff and the friends or relatives who accompany her to the hospital. When clinic staff encourage a woman to bring a relative or friend on the day of the NLP, they are facilitating a useful intervention which may well improve the patient's experience and which costs the hospital nothing. The same is true of recognizing and affirming any strategy of self-regulation the patient may choose to employ. Women are individuals. Some want as much information as possible about the NLP, others prefer a minimum of information. Some want the distraction of chatting with the technician, others prefer to focus on self-hypnosis or meditation in silence, without distraction. That clinic staff at the two hospitals of this study often and skillfully provided this kind of support is evident from the gratitude expressed by patients in many instances (see Appendix F).

The hypothesis that women who were given medication were more likely to report use of some form of self-regulation strategy was supported. The injection of lidocaine, as noted above, did not eliminate all pain and may even have resulted in pain or distress. The pain of the injection itself, the burning sensation of the infusion, missing the exact location that needed to be numbed, or the numbness wearing off before the procedure was finished are all examples of discomfort possibly experienced with the injection of medication to relieve pain. Women may have been prompted by such discomfort to practise a strategy of self-regulation, for example meditation, distraction, or relying on the social support of others, to make the NLP more tolerable. The provision of pain

medication also may have constituted a warning to women to prepare themselves for the NLP, whether or not they experienced any aspect of the injection as painful.

It was hypothesized that six variables might be expected to increase the incidence of pain, pain intensity and unpleasantness ("painfulness") and distress. Each of these variables seemed likely to increase a patient's physiological or psychological vulnerability to pain and distress in the course of the NLP. Past difficulty with such elements of the NLP as mammographic compression or needles, and anxiety about having a wire inserted into her breast would seem logically associated with a patient's increased NLP pain and distress. The same is true of worry about imminent surgery in view of past difficulty with surgery and worry about a cancer diagnosis. A woman reporting breast tenderness on the day of the procedure could reasonably be assumed to experience increased pain and distress in the course of the procedure.

None of the six variables proved to be correlated with pain incidence. However, there were statistically significant correlations between these variables and painfulness or distress. Looking only at the correlations above .30, breast tenderness is associated with painfulness in both the concurrent and retrospective samples. Anxiety about the NLP is associated with distress in both samples. In the concurrent sample, worry about possible cancer is associated with painfulness, whereas in the retrospective sample two variables, generally finding mammography a painful procedure and experiencing distress while having blood drawn, are significantly correlated with painfulness. These correlations suggest that several variables make an individual uniquely vulnerable to a painful or distressing NLP. The variables fall into three general categories: (1) recall of difficult past experiences (mammography and blood drawing); (2) apprehension about certain or

possible future experiences (anxiety about the NLP, worry about cancer); and (3) physiological characteristics (breast tenderness). Regression analysis reinforced two of the above findings. When the separate linear contributions of the six variables to painfulness and distress were analyzed in the retrospective sample, two statistically significant linear relationships emerged. One relationship is between generally finding mammography painful and ratings of NLP painfulness. The second is between prior anxiety about the NLP and reporting the procedure to be distressing. It may be useful to identify women who generally find mammography painful or who are highly anxious about the NLP and to intervene early with appropriate measures for their support.

A woman who generally finds mammography painful may dislike the invasiveness of the procedure and the exposure it entails. The sensitivity or size of her breasts may make mammographic compression particularly uncomfortable. Mammographic compression is prolonged during NLP and the explicitly invasive factors of needle insertion and guide wire placement may worsen the pain of the compression. If it is ascertained in advance that a patient generally finds mammography painful, then she can be offered support, including pain medication or an anxiolytic, and monitored especially carefully for her physical and emotional reaction to the procedure.

A woman may be anxious about the NLP for many reasons, including an aversion to medical procedures, a previous breast cancer diagnosis or death in her family, or knowledge of a friend's difficult experience of NLP. The unique circumstances of the patient undergoing the procedure will affect her perception of it. A woman who reports feeling anxious about the NLP is also a candidate for supportive interventions, including discussion of her concerns and fears, reassuring information, the continuous presence of a

clinic staff or family member throughout the NLP, and medication for anxiety and pain.

Other Findings

The pilot study completed in early 1994 suggested that some women find NLP an extremely difficult experience. This premise was confirmed in the present study. There was a wide range in women's perceptions of and reactions to the needle localization procedure. Some women write in vivid terms about their experience, as in the following examples: 1) "It's the squeezing of the breast that makes it so uncomfortable, as if they're tearing the breast away from your body, and then you're waiting for all those painful things to take place."; 2) "For a moment everything was black, with a red streak through it, at the time the needle was inserted. I nearly fainted. The lidocaine also stung at first."; 3) "[It was] humiliating, technical. I was embarrassed. People would open and close the door to [the] hall, passing in and out getting equipment or consulting with [the] doctor as I sat trapped in a machine."; 4) "It was quite painful and the sensation was disturbing. It took all my self-control not to vomit."

On the other hand, some women report an uneventful experience of NLP, as in these examples: 1) "I had no problems with it. Personnel [were] extremely helpful."; 2) "It was just so quick. It was over before I knew he put it in. I closed my eyes and didn't watch him. He was really good."; 3) It wasn't nearly as bad as I feared. I wouldn't want to do it very often, but it's not bad at all. I didn't think it was as bad as a regular mammogram."; 4) "I never had it done before, so of course I was a little anxious about it, but not scared to do it. It did not hurt at all."

Possible reasons for these varying reactions to NLP were explored in the present study. Other reasons are reflected in the many comments women themselves made when

they were asked about their physical and emotional reaction to the procedure, and when they were asked what they would suggest to make the experience as comfortable as possible for other patients (Appendix F). The reader's attention to these comments is encouraged. Women clearly state the importance of interactions with technicians, nurses and physicians. They offer much practical advice. They complain of the cool temperature of the room and of long waits. They make suggestions for redesigning the machinery for NLP. Many request sedation and numbing of the breast. They express appreciation for clear and complete information before and during the NLP and for the kindness and consideration shown them by clinic staff. The uniqueness of each woman and her experience is plain in these comments.

Data on yearly household income and level of education were averaged to provide an estimate of socio-economic status for each patient. Correlations of socio-economic status with pain incidence, NLP painfulness, and NLP distress were explored. The correlation of socio-economic status with pain incidence was not statistically significant ($r = .14$, $p > .05$). Neither was the correlation of socio-economic status with painfulness statistically significant ($r = -.23$, $p > .05$). The correlation of socio-economic status with NLP distress was only marginally statistically significant ($r = .32$, $p = .049$). This might reflect greater willingness to express distress, or a stronger sense of boundary violation experienced with this invasive procedure among patients of higher socio-economic status. However, the marginal nature of this result suggests great caution in any interpretation.

The small number of African-American women in the study ($N = 18$) made data comparisons with European-American women in the study ($N = 116$) unreliable. The reported incidence of pain among African-American and European-American women was

compared via chi-square analysis, $X^2(1, \underline{N} = 134) = 7.79$, $\underline{p} < .05$. There were only 5 African-American women reporting no pain, so few that reliable inferences cannot be drawn from the results of this analysis. Reported means for NLP painfulness among African-American women (5.77) and European-American women (4.31) were compared with a t-test, t(1, 86), p = .047. This result is likely to be an artifact of the small sample of African-American women ($\underline{n}$ = 13) making an unreliably high mean value for their ratings of painfulness compared with the much larger sample of European-American women ($\underline{n}$ = 74). Still, worry about the higher incidence of breast cancer in African-Americans or discomfort in a clinic largely staffed by European-Americans may increase NLP painfulness among African-American women. Comparing means for NLP distress among women in the two ethnic groups yielded results that were not statistically significant, t(1, 134), p > .05.

Theoretical and Clinical Significance

There is some controversy in the literature about the value of lidocaine as an intervention to relieve pain. At the time data were gathered for this study, this difference of opinion was reflected in the fact that at one of the hospitals, all women were given lidocaine as a matter of policy, while at the second hospital the decision was left up to the attending physicians. This study was modest in its scope and numbers of patients studied; however, findings suggest that NLP patients be offered lidocaine as a matter of policy. At the same time health care providers should recognize that lidocaine will not eliminate pain and may even cause some pain. Using buffered lidocaine that is prepared close to the time of need is likely to be less uncomfortable for patients than lidocaine that is not buffered.

For the very reason that even with lidocaine some women will continue to experience pain, additional interventions are important. There is very little exploration in the literature of women's pain during NLP or of interventions that might alleviate that pain and distress. This study makes a contribution to the field by pointing to the value of something that women are doing for themselves. Strategies of self-regulation can be recognized, encouraged, and taught to patients preparing themselves for the procedure. Support from clinic staff is especially important, in the form of kindness, encouragement, humor, considerate physical touch, and clear and complete information. Friends and relatives who accompany the patient can be recognized as members of the team of people who are doing their best to ensure that the patient is comfortable throughout the needle localization procedure. In addition, the attempt to identify individuals who are likely to have a difficult time demonstrated two relevant variables. If a patient generally finds mammography painful or if she is anxious about the NLP, she can be monitored carefully and offered continual support, information, and reassurance to make her experience of the NLP as comfortable as possible.

Limitations of the Study and Suggestions for Future Research

There are three main limitations of the study. The first is the inclusion of data both from concurrent and retrospective patients. Second, variations in the administration of the NLP and their effects on women's experiences of pain and distress were not examined. The third concerns the composition of the population studied: a slightly smaller than expected number of African-American women than is representative of the area in which the study took place and lack of inclusion in the study of Asian-American, Latina, or other women of ethnic and cultural minorities.

The need for adequate numbers of patients for the study led to the inclusion of data from women who were interviewed right after the NLP as well as from women who responded to a mailed survey months after the procedure. This was problematic for data analysis and led to analyzing the two samples separately as well as together. These two samples, concurrent and retrospective, showed statistically significant differences in some of their responses to questions. Seventy percent of the retrospective sample reported experiencing pain, whereas only 57% of the concurrent sample reported experiencing pain. Recall from Table 2 that the mean scores for the intensity and unpleasantness of pain, and for distress, were significantly higher for the retrospective sample. It is possible that in addition to the significant sample differences reported from any of the measured variables (lidocaine, self-regulation, knowledge of cancer diagnosis), the passage of time and the very different circumstances at the time of completing the survey may have influenced patient responses. Patients in the concurrent sample were interviewed when they were about to have surgical biopsy and soon would learn whether or not they had breast cancer. It is possible that they could not yet afford to acknowledge how painful or distressing the needle localization procedure was in view of the challenges still ahead for which they needed to muster courage and hope. Patients in the retrospective sample, on the other hand, may have been better able to acknowledge after some recuperation how painful or distressing the NLP was for them. The responses to pain questions of women in this sample with known breast cancer did not differ in a statistically significant way from women without breast cancer. Women with cancer in the retrospective sample may have remembered the NLP as a difficult start to a challenging ordeal overall.

It is worth noting that women in the retrospective sample may have considered not

simply the needle localization procedure but also their wait for surgery, the surgery itself, and complications following surgery in answering questions about the NLP. If these experiences were problematic, that may have affected responses to questions specifically about the NLP.

Gathering and analyzing data from a uniform sample, that is, only from concurrent or from retrospective patients, would have strengthened the reliability of the results. Another interesting approach would be to survey the same sample across time, both just after and perhaps six months after their experience of needle localization.

Breast needle localization is a medical procedure that can be administered in different ways. This study did not distinguish between patients who had one or multiple lesions, patients who, even if they had only one lesion, were subjected to more than one attempt to insert the guide wire, patients whose breast scar tissue made the guide wire insertion more difficult and painful, patients whose lesions were located deep within the breast and difficult of access rather than close to the surface of the breast, patients for whom the degree of mammographic compression was greater and its duration prolonged, patients who received buffered and non-buffered lidocaine, and patients who were conducted through the procedure by relatively more or relatively less experienced clinic staff. Instead, needle localization was regarded as a procedure that was the same for all women undergoing it. The above variations and others in the procedure must have accounted for at least some of the reported variations in patient response. More precise measure of these variations, many of which would be recorded in the medical records of the patient at the clinic where the NLP was performed, would help to identify the procedural differences that may have accounted for differing responses and would be

important for further study.

The response rate for returned surveys was 60%. It is impossible to know how the inclusion of the additional data would have affected the analyses. In one respect, however, those who responded seem to be proportionally representative of the entire retrospective sample. Among the women who did respond 17 (about 21 %) reported having been diagnosed with cancer. This is a reasonable and anticipated percentage of positive findings for the diagnostic procedure carried out, and it suggests that at least in this regard, those who responded were representative of the 145 surveyed.

In addition, the entire sample of 138 women is approximately representative of the ethnic mix found in the City of Charlottesville and surrounding Albemarle County, the main geographic area providing patients for the two hospitals. A little more than 15% of the city and county population is African-American, and about 13% ($\underline{n}$ = 18) of the sample is African-American. European-Americans make up about 81% of the city and county population and they number about 84% ($\underline{n}$ = 116) of the sample. Other ethnic groups in the area are quite small. The slightly smaller than expected numbers of African-Americans in the sample may reflect lower rates of screening mammography in this population or more difficult access to health care generally. Carrying out a similar study in a community with a larger African-American, Asian-American, Latina, or other minority population might provide useful information about self-regulation strategies that are culturally based, and useful insights into how women of varied ethnic and cultural backgrounds might best be supported through culturally appropriate interventions.

In addition to the above suggestions made for further study, it would be worthwhile exploring the influence of an anxiolytic given to patients before the NLP as an

additional intervention to reduce pain and distress. There were too few women in this sample who reported being given an anxiolytic to allow an evaluation of its impact.

Summary and Conclusions

This study confirms the need for and suggests the value of interventions like pain medication, social support, and other forms of self-regulation to address both the physical and psychological aspects of pain experienced during needle localization for breast biopsy. These interventions may help to decrease the physical sensation of pain, its intensity and unpleasantness, and feelings of distress. The results also suggest the value of identifying in advance women who, because they generally find mammography painful or because they are quite anxious about the procedure, may need extra support.

Medical procedures like the NLP may become fairly routine for those who carry them out time after time, week after week. The patient brings her own particular strengths and vulnerabilities to the procedure, however, and this makes each needle localization procedure unique. For most patients, the NLP is not a routine experience. Efforts must be made to make the procedure as comfortable and tolerable as possible for all patients. The experience of extreme pain described by some women in this study should be deemed unacceptable. Until it becomes possible to predict with certainty which patients are going to have a difficult experience, it would be wise to heed a woman in the pilot survey, who advised the following:

> You may find that women vary widely in their description of the pain; please don't assume that those who say it's horrible are wimps! From what I've read, breast tissue varies greatly in sensitivity, and not a single woman should have to undergo this experience with terrible pain. And please don't let anyone discount someone's pain by saying that the patient is tense or emotional. Of course she is! Someone has raised the possibility that she has cancer. *Assume* she's tense and emotional and treat her with sensitivity.

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Appendix A: CONCURRENT FORM

No. _____

Needle Localization Survey (C)

Patient Name _____ **Date**_____

1. Was this your first experience of guide wire insertion for breast biopsy? Yes____ No____

2. Approximate date(s) of previous guide wire insertion procedure(s), if any _____

3. Hospital(s) where guide wire insertion occurred: _____

4. During today's guide wire insertion, did you experience pain? Yes_____ No____

5. *If you answered "yes"* to question 4, how intense was the pain sensation? (circle the number that applies to you)

No pain sensation	1	2	3	4	5	6	7	8	9	10 Most intense pain sensation imaginable

6. *If you answered "yes"* to question 4, how unpleasant or disturbing was the pain? (circle the number that applies to you)

Not at all unpleasant	1	2	3	4	5	6	7	8	9 Most unpleasant imaginable

7. Whether or not you experienced pain, did you find the guide wire insertion upsetting or distressing?

Not at all upsetting	1	2	3	4	5	6	7	8	9	10 Most upsetting imaginable

8. Please rate your level of anxiety about the guide wire insertion *before* having it done:

Not at all anxious	1	2	3	4	5	6	7	8	9	10 Most anxious imaginable

9. Were you given and/or did you take any medication to make you more comfortable during the procedure? No_____Yes_____ (Please explain):

10. Did you do anything else to make the experience more comfortable or tolerable (for example, distract yourself by concentrating on pleasant thoughts)? No_____ Yes_____ (Please explain):

11. How would you compare today's experience of guide wire insertion with any previous experience of guide wire insertion?

No prior experience_____ Less painful_____ About the same_____ More painful_____

12. Please briefly describe your physical and emotional reaction to the procedure: (Please add a separate page if additional space is needed)

13. What would you want doctors to know about your experience so they can make guide wire insertion as comfortable as possible for other patients? (Please add a separate page if additional space is needed)

14. Please rank the following events from the least to the most *painful*, where 1 = least painful, and 5 = most painful. Put <u>one</u> number by each item, and use *each* number only once.

_____Stubbing a toe
_____Giving birth
_____Having blood drawn
_____Having a guide wire inserted
_____Breaking a bone

15. Please rank the following from the least to the most *upsetting/distressing*, where 1 = least, and 5 = most upsetting/distressing. Put <u>one</u> number by each item, and use *each* number only once.

_____Stubbing a toe
_____Giving birth
_____Having blood drawn
_____Having a guide wire inserted
_____Breaking a bone

16. How worried are you about a possible diagnosis of breast cancer?

Not at all worried	1	2	3	4	5	6	7	8	9	10	Extremely worried

17. Are you currently *either* menopausal or post-menopausal? Yes_____ No_____

18. *If you answered "yes"* to question 17, please rate the degree of breast tenderness and/or pain you generally experience:

Not at all tender	1	2	3	4	5	6	7	8	9	10	Extremely tender

19. *If you answered "no"* to question 17, please indicate your current menstrual status:

A._____7 or fewer days before start of menstrual period.
B._____Any other time during or after menstrual period.

Please rate the degree of breast tenderness and/or pain you generally experience at this time of your menstrual period:

Not at all tender	1	2	3	4	5	6	7	8	9	10	Extremely tender

20. Do you generally find mammography a painful procedure?

21. Were you experiencing breast tenderness and/or pain today before you came in for the guide wire insertion?

Not at all tender	1	2	3	4	5	6	7	8	9	10 Extremely tender

22. Approximately how many cups of decaffeinated beverages do you drink daily? _____

23. Have you ever had surgery *other* than breast biopsy? Yes_____ No_____

24. *If you answered "yes"* to question 23, was your experience of other surgery difficult for you?

Not at all difficult	1	2	3	4	5	6	7	8	9	10 Most difficult imaginable

25. Please rate the level of pain during your **most recent** experience of having blood drawn (circle the number that applies to you):

No paid at all	1	2	3	4	5	6	7	8	9	10 Worst pain imaginable

26. Whether or not you experienced pain, please rate how upsetting or distressing you found that experience of having blood drawn:

Not at all upsetting	1	2	3	4	5	6	7	8	9	10 Most upsetting imaginable

27. Please rate the level of anxiety you felt about having blood drawn *before* having it done:

Not at all anxious	1	2	3	4	5	6	7	8	9	10 Most anxious imaginable

28. Age: _____

29. Education — highest level of school completed:

_____Less than 8th grade
_____Completed 8th grade
_____Completed high school
_____Some college
_____Completed college
_____Technical or business school
_____Graduate or professional school

30. Ethnic Group:

_____African-American
_____Asian-American
_____Caucasian
_____Latina
_____Other (please explain)

31. Yearly **household** income from all sources:

_____Less than $10,000
_____$10,000-20,000
_____$20,000-40,000
_____$40,000-60,000
_____Over $60,000

Appendix B: RETROSPECTIVE FORM

No. _____

Needle Localization Survey (R)

Patient Name:_____ **Date:**_____

1. How many times have you experienced guide wire insertion for breast biopsy?:_____

2. Approximate date(s) of guide wire insertion procedure(s):_____

3. Hospital(s) where guide wire insertion occurred:_____

4. During your **most recent** experience of guide wire insertion, did you experience pain? Yes___No___

5. *If you answered "yes"* to question 4, how intense was the pain sensation? (circle the number that applies to you)

No pain sensation	1	2	3	4	5	6	7	8	9	10	Most intense pain sensation imaginable

6. *If you answered "yes"* to question 4, how unpleasant or disturbing was the pain? (circle the number that applies to you)

Not at all unpleasant	1	2	3	4	5	6	7	8	9	10	Most unpleasant imaginable

7. Whether or not you experienced pain, did you find the most recent guide wire insertion upsetting or distressing?

Not at all upsetting	1	2	3	4	5	6	7	8	9	10	Most upsetting imaginable

8. Please rate your level of anxiety about the most recent guide wire insertion *before* having it done:

Not at all anxious	1	2	3	4	5	6	7	8	9	10	Most anxious imaginable

9. Were you given and/or did you take any medication to make you more comfortable during the procedure? No____ Yes____ (Please explain):

10. Did you do anything else to make the experience more comfortable or tolerable (for example, distract yourself by concentrating on pleasant thoughts)? No____ Yes____ (Please explain):

11. How would you compare the most recent experience of guide wire insertion with any previous experience of guide wire insertion?

No previous experience_____ Less painful_____ About the same_____ More painful_____

12. Please briefly describe your physical and emotional reaction to guide wire insertion: (Please add a separate page if additional space is needed)

13. What would you want doctors to know about your experience so they can make guide wire insertion as comfortable as possible for other patients? (Please add a separate page if additional space is needed)

14. Please rank the following events from the least to the most *painful*, where 1= least painful, and 5 = most painful. Put <u>one</u> number by each item, and use *each* number only once.

_____Stubbing a toe
_____Giving birth
_____Having blood drawn
_____Having a guide wire inserted
_____Breaking a bone

15. Please rank the following from the least to the most *upsetting/distressing*, where 1 = least, and 5 = most upsetting/distressing. Put <u>one</u> number by each item, and use *each* number only once.

_____Stubbing a toe
_____Giving birth
_____Having blood drawn
_____Having a guide wire inserted
_____Breaking a bone

16. Was breast cancer diagnosed following your guide wire insertion experience? No___ If Yes, approximate date:_____

17. At the time of your most recent guide wire insertion, were you *either* menopausal or post-menopausal? Yes____ No____

18. *If you answered "yes"* to question 17, please rate the degree of breast tenderness and/or pain you generally experienced:

Not at all tender	1	2	3	4	5	6	7	8	9	10 Extremely tender

19. *If you answered "no"* to question 17, please indicate your menstrual status at the time of your most recent guide wire insertion:

A._____7 or fewer days before start of menstrual period
B._____Any other time during or after menstrual period

Please rate the degree of breast tenderness and/or pain you generally experienced at that time of your menstrual period:

Not at all tender	1	2	3	4	5	6	7	8	9	10 Extremely tender

20. Do you generally find mammography a painful procedure?

Not at all painful	1	2	3	4	5	6	7	8	9	10 Most painful imaginable

21. On the day you went in to have the most recent guide wire insertion, as best you can remember, were you experiencing breast tenderness and/or pain? Yes____ No____

22. As best you can remember, approximately how many cups of caffeinated beverages were you drinking daily at the time of your most recent guide wire insertion?_____

23. Have you ever had surgery *other* than breast biopsy?
No_____. If Yes, approximate date(s): _____

24.. *If you answered "Yes"* to question 23, was your experience of other surgery difficult for you? (circle the number that applies to you):

Not at all difficult	1	2	3	4	5	6	7	8	9	10 Most difficult imaginable

Please explain briefly:_____

_____

25. Please rate the level of pain you experienced the last time you had blood drawn (circle the number that applies to you):

No pain at all	1	2	3	4	5	6	7	8	9	10 Worst pain imaginable

26. Whether or not you had pain, please rate how upsetting or distressing you found that experience of having blood drawn:

Not at all upsetting	1	2	3	4	5	6	7	8	9	10 Most upsetting imaginable

27. Please rate the level of anxiety you felt about having blood drawn *before* having it done:

Not at all anxious	1	2	3	4	5	6	7	8	9	10 Most anxious imaginable

28. Age:_____

29. Education—highest level of school completed:

_____Less than 8th grade
_____Completed 8th grade
_____Completed high school
_____Some college
_____Completed college
_____Technical or business school
_____Graduate or professional degree

30. Ethnic Group:

_____African-American
_____Asian-American
_____Caucasian
_____Latina
_____Other (please explain)

31. Yearly **household** income from all sources:

_____Less than $10,000
_____$10,000-20,000
_____$20,000-40,000
_____$40,000-60,000
_____over $60,000

Appendix C: COVER LETTER

UNIVERSITY OF VIRGINIA
HEALTH SCIENCES CENTER
DEPARTMENT OF ANESTHESIOLOGY
PAIN MANAGEMENT CENTER

Dear Ms.

We are carrying out a survey of women who have experienced needle localization (guide wire insertion) prior to breast biopsy. Very little has been studied about the response of women to this procedure. We want to know more about women's experience with guide wire insertion in order to determine whether or not additional preparation or interventions should be offered to make the procedure as comfortable as possible for all patients.

We would very much appreciate your taking time to fill out the enclosed survey form, and to return it at your earliest convenience in the self-addressed stamped envelope provided. It will take approximately 20 minutes to complete the form. The information gathered will be analyzed and presented to assist physicians in making decisions about how best to support women undergoing guide wire insertion.

Confidentiality of your responses will be preserved. Only the undersigned researchers and a research assistant will have access to the survey forms, and your responses will be recorded using an identification number. The results of the study may be published in the medical literature, but no publication will contain information that will identify you.

If you have questions or concerns about any aspect of this study, please feel free to contact us. We are grateful for your assistance in helping us document women's experience of guide wire insertion. Thank you very much.

Sincerely yours,

Marian De W. Morgan, M.A., M.P.H.
(804) 974-6239

Joseph R. Dane, Ph.D.
Clinical Psychologist
Assistant Professor of Anesthesiology
Pain Management Center
Acute Pain Service Psychology Division
(804) 924-1648

Appendix D: FOLLOW-UP LETTER

UNIVERSITY OF VIRGINIA
HEALTH SCIENCES CENTER
DEPARTMENT OF ANESTHESIOLOGY
PAIN MANAGEMENT CENTER

Dear Ms.

Several weeks ago, we mailed a brief survey form to women who have experienced needle localization (guide wire insertion) prior to breast biopsy. Knowing how women respond to this procedure will help to determine whether or not additional preparation or interventions should be offered to make guide wire insertion as comfortable as possible for all patients.

Your response is important to us. We are enclosing a second copy of the survey in case it has been mislaid, with the hope that you will be able to complete and return the survey as soon as possible. It will take approximately 20 minutes to complete the form, and we have provided a self-addressed stamped envelope for your convenience. We would be very grateful for your assistance.

Confidentiality of your responses will be preserved. Only the undersigned researchers and a research assistant will have access to the survey forms, and your responses will be recorded using an identification number. The results of the study may be published in the medical literature, but no publication will contain information that will identify you.

If you have questions or concerns about any aspect of this study, please feel free to contact us. We appreciate your assistance in helping us document women's experience of guide wire insertion. Thank you very much.

Sincerely yours,

Marian De W. Morgan

Marian De W. Morgan, M.A., M.P.H.
(804) 974-6239

Joseph R. Dane, Ph.D.
Clinical Psychologist
Assistant Professor of Anesthesiology
Pain Management Center
Acute Pain Service Psychology Division
(804) 924-1648

Appendix E: PILOT SURVEY AND PATIENT COMMENTS

Needle Localization Survey (Pilot R)

Patient Name:_____ **Date:**_____

1. How many times have you experienced guide wire insertion for breast biopsy? _____

2. Approximate date(s) of guide wire insertion procedures(s):_____

3. Hospital(s) where guide wire insertion occurred:_____

4. During your most recent experience of guide wire insertion, did you experience pain? (circle the number that applies to you)

No pain at all — somewhat — Worst possible pain imaginable

1 2 3 4 5 6 7 8 9 10

5. Whether or not you experienced pain, did you find the most recent insertion of the guide wire upsetting or distressing?

Not at all — somewhat — Extremely

1 2 3 4 5 6 7 8 9 10

6. Were you anxious about the most recent guide wire insertion *before* having it done?

Not at all — somewhat — Extremely

1 2 3 4 5 6 7 8 9 10

7. Did you receive any medication to make you more comfortable during the procedure? Yes___ No___

8. How would you compare the most recent experience of guide wire insertion with any previous experience of guide wire insertion?

_____Less painful _____About the same _____More painful _____No prior experience

9. Please briefly describe your physical and emotional reaction to guide wire insertion: (Please add a separate page if additional space is needed)

10. What would you want doctors to know about your experience so they can make the guide wire insertion as comfortable as possible for you and for other patients? (Please add a separate page if additional space is needed)

11. Please rank the following from least (= 1) to most (= 7) *painful*, according to how painful you believe each experience is, whether or not you have actually experienced it. Put <u>one</u> number by each item.

_____Stubbing your toe
_____Giving birth
_____Getting a shot
_____Having a guide wire inserted
_____Breaking a bone
_____Getting a tooth filled
_____Burning your hand

12. Please rank the following from least (=1) to most (=7) *upsetting/distressing*, according to how upsetting/distressing you believe each experience is, whether or not you have actually experienced it.

_____Stubbing your toe
_____Giving birth
_____Getting a shot
_____Having a guide wire inserted
_____Breaking a bone
_____Getting a tooth filled
_____Burning your hand

13. Was breast cancer diagnosed following your guide wire insertion experience?

No____ If Yes, approximate date _____

14. Have you ever had surgery *other* than breast biopsy?

No____ If Yes, approximate date(s) _____

15. If you answered "yes" to question 14, was your experience of other surgery difficult for you? (circle the number that applies to you)

Not at all Somewhat Extremely

1 2 3 4 5 6 7 8 9 10

Please explain briefly:_____

_____

16. As best you can remember, approximately how many cups of regular coffee were you drinking daily at the time of your most recent guide wire insertion?_____

17. Do you generally find mammography a painful procedure?

Not at all Somewhat Extremely

1 2 3 4 5 6 7 8 9 10

18. At the time of your most recent guide wire insertion, what was your menstrual status as best you can recall?

A._____Menopausal
B._____7 or fewer days before start of menstrual period
C._____Any other time during or after menstrual period

19. If you checked "A" in question 18, do you generally experience breast tenderness and/or pain?

Not at all Somewhat Extremely

1 2 3 4 5 6 7 8 9 10

20. If you checked "B" in question 18, do you generally experience breast tenderness and/or pain during the week before your menstrual period?

Not at all Somewhat Extremely

1 2 3 4 5 6 7 8 9 10

21. If you checked "C" in question 18, do you generally experience breast tenderness and/or pain at other times than during the week before your menstrual period?

Not at all Somewhat Extremely

1 2 3 4 5 6 7 8 9 10

Demographic Data

22. Age: _____

23. Education — Highest Level of School Completed:

_____Less than 8th grade
_____Completed 8th grade
_____Completed high school
_____Some college
_____Completed college
_____Technical or business school
_____Graduate or professional degree

24. Ethnic Group:

_____African-American
_____Asian-American
_____Caucasian
_____Latina
_____Other (please explain)

25. Yearly family income from all sources:

_____Less than $10,000
_____$10,000-20,000
_____$20,000-40,000
_____$40,000-60,000
_____Over $60,000

Your Comments on the Pilot Survey (Questions 1-25):

1. Is the survey form respectful?

2. Is any question unclear? Please explain:

3. Should we ask about anything else?

4. About how long did it take you to complete the form?

5. Other comments or suggestions:

Thank you very much for your help with this study
of women's experience of needle localization.

Pilot Survey Patient Comments:

1. [Excerpts from long letter]: I am quite pleased to learn that you are inquiring into the experience of undergoing a breast biopsy wire insert.... I found my two insert experiences at [hospital] to be so painful that I wrote both my gynecologist and surgeon to express my incredulity that women would be subjected to such a painful, dehumanizing experience in this day and age.... When I inquired as to why no pain relief was provided, I was told that a shot would be as painful as the insertion. I find this unbelievable. During both of my needle inserts, the wire had to be moved several times within my breast while I was squeezed between the mammography plates. The pain was quite terrible.... You may find that women vary widely in their description of the pain; please don't assume that those who say it's horrible are wimps! From what I've read, breast tissue varies greatly in sensitivity, and not a single woman should have to undergo this experience with terrible pain. And please don't let anyone discount someone's pain by saying the patient is tense or emotional. Of course she is! Someone has raised the possibility that she may have breast cancer. *Assume* she's tense and emotional and treat her with sensitivity.

2. It was more painful than I expected (I had 2 guide wire insertions because the first one was not placed well). It's more than "a little stick."

3. Secondary to anxiety re potential breast cancer I was less relaxed therefore more apprehensive about procedure, this increased pain level. Emotional support, complete explanation of the procedure and frequent reassurance diminish the anxiety level.

4. First experience painful: experienced syncope, very unhappy with process, care providers impersonal. Second experience with self-hypnosis far less traumatizing: little discomfort, no syncope. A caring environment is conducive to a better experience. The procedure is uncomfortable. Give encouragement, be accepting of alternate methods of coping, i.e. self-hypnosis.

5. Emotional [reaction]: mother and aunt both died from CA, primary site breast, so naturally I am anxious and worried anytime there is an abnormality found. Physical [reaction]: the breast being compressed is extremely uncomfortable. When checking wire placement, take x-rays and read as quickly as possible. I was in an uncomfortable position and had to remain so through two sets of films; [it would be] nice to have some diversion.

6. The first time I had it in April 1990 I almost fainted. The second time I got along much better. Make it less painful.

7. The pain was extremely intense and I was very angry that there seemed to be no empathy for me [from] the health care personnel. There seemed to be this "surprise" that it could possible be painful. Be aware of the pain caused by the procedure, explain what the experience might entail (don't scare the patient but be honest with information). As a health care professional, I have <u>always</u> felt that a patient has the right to know what to expect (I have had to do many "less than comfortable" procedures on patients). The

person performing the procedure should understand (as best they can) what effect the procedure will have on the individual. Surprises—that are painful—are cruel and unnecessary. In the future, I would avoid this procedure if at all possible. My mother and my mother-in-law have both had it done and their experiences have been very similar.

8. Physical [reaction]: benign. Emotional [reaction]: fear and anxiety about the procedure which was probably more about outcome but focused on the concrete. [Offer] emotional support and recognition that fear of the unknown is much harder to deal with. I hope I never have a repeat but if I do, I will not be anxious about the procedure just the result.

9. I experienced quite a bit of pain but realized the procedure was necessary, so I clenched my teeth and bore the discomfort. Would it be possible to numb the breast?

Appendix F: PATIENT RESPONSES TO OPEN-ENDED QUESTIONS

Patient Responses to Open-ended Questions

Three questions invited women to comment on their experience of needle localization. These questions concerned any self-regulation strategy a woman may have used, her physical and emotional reaction to the NLP, and her advice to doctors. The wording of the questions was as follows:

10. Did you do anything else to make the experience more comfortable or tolerable (for example, distract yourself by concentrating on pleasant thoughts)?
12. Please briefly describe your physical and emotional reaction to the procedure.
13. What would you want doctors to know about your experience so they can make guide wire insertion as comfortable as possible for other patients?

The comments listed below are identified by patient number and question number. A few patients made no comments. In some cases, patients added comments elsewhere on the survey form that were relevant to the questions listed above. Such comments are identified as 'O' for other.

1. 10. Thinking positive.
   12. I'm feeling shaky.

2. 12. I wasn't happy about it, but I knew it had to be done. I don't want to walk around with something abnormal. I tell you, you come up here feeling good, and you go out feeling bad.
   13. Be careful about the needle—that did hurt me when it was moved inside me. I would much rather have an IV to put me to sleep. If they would use some more needles I'd want to be put to sleep. I felt that point when my breast was pushed. I expected the prick, but not the sharpness.

3. 10. I closed my eyes and thought of being somewhere else.
   12. It was not painful. It bothered me that the staff began to put the wrong breast in the machine.

4. 10. I thought about how nice the x-ray tech was.
   12. Do not want to do again.
   13. Numbing area.

5. 10. I clung to two people and looked away.
   12. It stung a little bit afterwards, but that can't be helped.
   13. Put blinders on the patient. You don't need to tell them that that's what you're doing but just so they can't see. If people are kind to you and joke with you a little bit and call you darling it helps.

6. 12. My thoughts were scary until I was made by the doctors and nurses to feel a lot more relaxed.

13. Just making the patient feel like at that time they are the most important person in that room. Which they do!

7. 13. Numb the area

8. 10. Talking with the doctor helps.
12. The wire hurt.

9. 10. I distracted myself and crossed my fingers and focused on varying the pressure, as I do at the dentist's.
12. Stress.
13. Telling me what was happening was very helpful; relaxed, assured voices calmed; sense of routine procedure was helpful; teamwork between doctor and assistant; polite sensitivity toward me as a person.
O. When given info and allowed to participate, stress and fear are less.

10. 10. Pulled white light into my chest.
12. Reasonable—not very stressful. I was given lidocaine and it stung. I didn't expect that and wasn't warned.
13. Tell people before inserting pain medication so they are not startled by the sting.

11. 12. Things are always better than expected. I don't feel pain. [Pt. gave examples of high threshold for pain but added that she is very anxious about needles.] I preferred no anesthesia because it would have meant an extra needle stick.

12. 12. Matter-of-fact. [Pt. commented that she had refused to have an NLP the previous year: "I was mad; I'd had it done too many times. Now I think I should have." However, when told on this occasion she had to have the NLP repeated to ensure precise location of microcalcifications for surgery, pt. at first refused, saying "It's my body." Then she said "Oh go ahead, do what you have to."]
O. [Pt. was offered but declined lidocaine to numb the area before NLP. Her comment: "I don't want to be like a baby."]

13. O. After the first wire I had to have something to deaden the pain.
12. The physician was very helpful and polite and understanding.
13. I think anytime you have a guide wire inserted you should have a shot tonumb the pain just in case you do have pain.

14. 13. Today was very good. I expected more pain with the wire.

15. O. I faint if I see blood, but needles don't bother me otherwise.

16. 12. No reaction.

17. 10. Tried not looking, not thinking about the situation.
12. It was too much occurring at one time. Immediately after the lidocaine was administered I felt burning, my ears felt stopped up and ringing and my heart rate felt like it increased. When she began to insert the wires I did begin to pass out and I was immediately lain down. On the second attempt I started to pass out again. It may be with the compression of the breast, the lidocaine and the wire insertion it was too much happening at once.

18. 10. Practicing the relaxation response. I meditate daily. I was using relaxation techniques.
12. I felt it was a necessary procedure. The compression was uncomfortable but it was relatively short. I feel the relaxation techniques were invaluable. All in all it wasn't too bad.

19. 10. The lady who came over and held my hand was wonderful. I was so scared I had my head turned away, and that meant the world to me. When the lady came around to be with me as a friend that helped me more than anything.
12. I was frightened, afraid of the pain. In the end it was less pain than I imagined. I wish when we came to the hospital there was something they could do so there wasn't any pain.
13. It's the squeezing of the breast that makes it so uncomfortable, as if they're tearing the breast away from your body, and then you're waiting for all those painful things to take place. The pillow case on the pillow was leather, and it was damp and unpleasant. [Pt. also complained of having strained her right shoulder during the procedure.]
O. I don't like needles.

20. 10. Knew it would be over soon.
12. Calm.

21. 10. Talked with technicians and doctor.
12. Feared it would be dreadful but very pleasantly surprised by the ease of it all. I expected the worst because of what friends had told me.
13. The doctor's attitude was very reassuring. Calmness, competency, and he didn't appear rushed. I didn't feel as if I were taking him away from something important to him.

22. 10. After I found out what it was all about I just kind of 'go with the flow.'
12. If I've got to do it, I just go ahead and do it. I don't worry about it. They just told me what was going to happen and it was going to happen, so.... I've just resigned myself to whatever happens. The older you get, you resign yourself to things that happen. I think the younger people worry more than we do.
13. Explain the procedure in plain language. That was very helpful. It wasn't hard for me. If you're kept in the dark you worry about things.

23. 10. Prayed.
12. Hurt a little when they put the numbing medicine in.
13. They were supportive and caring, asking me if I was all right.

24. 10. Calmed my brain, visualized tranquil scene. I would have done deep breathing exercises, but could not, being pressed.
12. Low key, but feeling a bit anxious.
13. I want to say that all the staff was so supportive and comforting, and (most importantly) explaining every step of the procedure, that it made a tremendous difference of emotional comfort and support.

25. 12. What I experienced wasn't bad at all—just like a bee sting.

26. 10. Chatted with U. [technician] about jewelry, music, etc.
12. So far everything has gone pretty smoothly. I appreciate the tender care and concern of the people who did it.
13. Just that an atmosphere of caring attention helps so much.

27. 10. I had to tell myself to relax. I focused on relaxing my hand which was gripping the bar. I pretended I was somewhere else—notably in my bed.
12. Physically—a little uncomfortable from the squeezing but not bad. M., the lab technician, was very friendly. She and the other tech. explained everything that was going on. They treated me with respect. I became involved in talking with M. so didn't focus as much on the 'happening'. Emotional reaction—OK at this time. Very calm. I prayed that all would go well. I've been through previous surgeries and know that this is something that needs to be done.
13. My doctor explained the procedure ahead of time. The technicians told me, in detail, everything they were doing. They were very calm and matter-of-fact. The doctor was excellent for the same reasons. All of the above contributed to my comfort. The machine is cold and the room was cool which made me uncomfortable for a short time. Could someone invent a warm machine? I liked receiving the flowers.

28. 12. No problem.
13. The most difficult part is the waiting and waiting. The other day I had an appointment with the doctor at 10:30, and I didn't leave the hospital until 2:30.

29. 12. The room was larger, the technicians were fantastic. They talked to me and kept my thoughts occupied so I wasn't concerned about the procedure.
13. Having been through this before I was prepared as to the events taking place.

30. 12. The unknown is frightening.
13. No problem.

31. 12. The procedure was not really bad, I feel the 'not knowing' part is the worst.

There is some pain when they're trying to position the breast for this procedure but it really was not that bad. Everyone was extremely nice and explained things very well.
13. No opinion because I feel Dr. S. did an excellent job.
O. I feel if surgery is required then I need to have a positive outlook and things will be OK.

32. 12. Arm got a little numb by the way it was lying.

33. 12. It is so very upsetting to wait, and when people are not prepared, and they do more than they say they'll do. Too much waiting, and not treating people as people but as flesh, a number. If I can never come back to the [hospital] I will not. The red tape is terrible.
13. Tell the complete truth about what is going to happen. Make the schedule work.
O. To tell you the truth they misled me—just told me about needles, not wires: 'you will get one needle in.' You should not treat old people like this.

34. 10. Prayer.
12. For a moment everything was black, with a red streak through it, at the time the needle was inserted. I nearly fainted. The lidocaine also stung at first. [But] I always accept things. 'It's there, let's get it out, let's get it over with.'
13. He was very straightforward, very honest. Dr. B. said I could have it out or wait six months. It's a matter of trust and faith. The two ladies were fantastic. Explained what they were doing and tried to make me feel comfortable and safe as possible. The location made stronger compression necessary.

35. 10. I just tried to be calm but that's hard to do when they're putting a wire in your breast.
12. I was really, really scared of this. The thought of a wire going in my breast was awful. I had tenderness in my left breast for years after a hysterectomy.
13. It's not bad right now.
O. I don't care for a wire going in my breast, thinking about infection. I wish they had given me something for my nerves.

36. 10. I just waited for them to do it.
12. I didn't think I had any in particular. The technician talked to me about her two-year-old. Just wanted to get it over with. If they're going to do it, they're going to do it.
13. Don't think they could have done anything else as far as I know. Dr. M. explained everything.

37. 10. Had friend in room with me.
12. Due to the complications of the previous procedure I was very anxious and upset with the thought of having to go through all of this again. My sleep

throughout the weekend was interrupted and this morning my stomach was slightly upset.
13. Let them know that the position you will be in is somewhat uncomfortable—after 20 minutes or so your neck gets a little stiff.

38. 10. I lean on Him and trust Him, so I didn't pay too much mind.
12. Get it done, get it over with, that's my feeling. Needles were a little uncomfortable, but it wasn't bad. It stings a little bit when they put the needles in, but it really didn't bother me. You have some good doctors and nurses up here. Everybody's fine. I appreciate their patience.
13. They were real good and co-operative to me. The lady stayed with me the whole time.

39. 10. A young person came in to talk and be with me while waiting for the x-rays to be read.
12. I think the staff acted in a very professional way.

40. 12. Nothing I looked forward to but not really a painful experience.
13. Having had the doctor tell me it would not be a painful experience kept me from worrying unduly.

41. 10. I considered the value of precautionary procedures and early detection of cancers. I also brought along a humorous book to read during 'wait time.'
12. Physical: some discomfort. Emotional: some distress because so many mammogram films were required.

42. 12. I am glad to see such careful follow-up being done. Glad to know a spot of five years duration is finally investigated. [Pt. was very angry with doctor in her hometown who failed to inform her she had a noticeable lesion five years earlier.]
13. All right as is.

43. 10. I just didn't think about it period. I told my husband but no-one else before Christmas. If you concentrate on everyone else you can't think about yourself.
12. They were very kind and easy with me, and didn't do anything to make me feel embarrassed or distressed. I'm worried about what this is going to turn out to be. If they can pinpoint this then it's worthwhile.
13. The only thing is just to explain to them and tell them what's going to happen. When they talk with you and tell you what's going to happen, it takes the stress out of it. When everything's kept a secret that's when you get scared.
O. [Re NLP] I didn't know what to do—like making a brand new cake and not knowing what to do [but] if I pay a doctor and trust him, I don't question him. I am extremely worried but I'm keeping my mind a blank. [Re mammography] I don't have much there, so it hurts when you've got somebody pushing and grunting to get you in there.

44. 10. I tried not to think about it. They went on about their business.
12. I first said I wasn't going to do it, then made up my mind I would. No use going to the doctor if you don't do what he tells you. I was most upset when I was told I had to come back.
13. I don't know of anything. It wasn't too bad.

45. 10. Breathed deeply.
12. Staff that took care of me helped make this experience not bad at all. If they treat everybody like that, they'll be OK.

46. 10. A lady was there, and talked to me the whole time—she never left me. The doctor and nurse were very special.
12. Dr. M. was great, and the nurse. He explained each step, when the needle was being inserted and explained x-ray to me. The people make a great difference.
13. I don't see how my doctor could have been any better at the whole procedure. The needle depends on who puts it in.

47. 10. I talked to the little nurse there.
12. What needs to be done, needs to be done. I am a pragmatic person.
13. Less pressure during mammogram—new technology?

48. 10. Just relaxed.
12. I had no problems with it. Personnel extremely helpful.

49. 12. Things are always worse in your mind than they turn out to be. I had no problem with it.

50. 12. I didn't mind having it done.

51. 10. The technician is a friend. She stayed with me the whole time.
12. It was stressful anticipating the procedure. I was told it was the worst part, but it was really OK.

53. 10. Talked to nurses, prayed, used heating pad and blanket.
12. Relief when pressure was released. Bled a bit when he took the needle out, but OK. He even got me a clean gown.
13. Do as quickly as possible.

54. 10. My husband was in there quite a bit. If you do have a loved one with you it helps whole lot. The lady who was in there was really nice. I'm glad she didn't say no he can't come in.
12. A nurse said my husband could drop me off and come back and pick me up later. What world does she come from? I anticipated it would be worse than it was. I've had diarrhea for the last three days because of nervousness, worry about results.

13. I think they did great. I hate this [pt. indicated IV] but she did a little numbing there on the hand with a needle, and it made a world of difference. I'm sensitive to pain and the lidocaine helped so much. My breast is aching now.

55. 10. Talk to the nurse.
12. The procedure was fine. I'm just worried if it will be bad news or good news
13. I don't really know. They were very nice to me.

56. 10. When he came with the wire I gritted my teeth. There were two nurses there, and they were talking. That helped.

57. 10. I prayed for strength.
12. I realized: think positive. I was a little nervous.

58. 10. The nurse told me to think of something pretty, like spring flowers. I told her a redbird, and she laughed.
12. It was just so quick. It was over with before I knew he put it in. I closed my eyes and didn't watch him. He was really good.
13. I don't think it could have been any better. Whoever was working was so encouraging that it wouldn't hurt. I kept my eyes shut and didn't see it and didn't feel it.

59. 10. Kept a good humor.
12. It wasn't nearly as bad as I feared. I wouldn't want to do it very often, but it's not bad at all. I didn't think it was as bad as a regular mammogram.
13. It hurts up under your arm where the corner of that mammogram tray is. They should make that less pointy or cushiony or something. That's by far the worst part of the whole thing.

60. [Pt. appended a page of comments.]

I was very anxious when told I needed to get the guide wire insertion. I was terrified in my mind. I just knew it was going to be awfully painful. I even put it off for a month and there were lots of sleepless nights. I knew this was something I had to do. It could mean my life. I thought if I had cancer, it might save my life if found early enough. So I began to think no matter how much I was afraid it had to be done, no matter how much it was going to hurt. I had made up my mind I would keep the appointment and that morning when I got up to go to Charlottesville all my fears were gone.

The doctor that put in the guide wire was great at his job. He hit the right spot, there was only a small amount of pain, nobody could have done it better. It was a piece of cake to what I thought it would be. I was so relieved. The mammography is a little painful with the wire insertion because they have to do it so many times to make sure it is in the right spot. The worst part of it all was the IV they put in for the operation to do the biopsy and lump removal. The university is a great health center. I have been going there for a few years and I have

experienced very little pain from their tests. They have great doctors.

If I have to have another guide wire insertion I would be afraid because next time it may not go that great. I have small breasts and that may be one reason it wasn't bad. I know some other women that had it. They said it was awful, but they have larger breasts. I can only speak for myself, and I say it wasn't bad at all.

61. 13. I was very satisfied with my treatment.

62. 12. It was painful but I knew it had to be done. Emotionally, I was very anxious about the results.
13. Staff was really wonderful and understanding.

65. 12. Anxious—but felt it was necessary.
13. Don't really know. Wish there was something less painful—and more comfortable.

66. 12. I never had it done before, so of course I was a little anxious about it, but not scared to do it. It did not hurt at all.
13. I don't think they could have done any more. Everyone explained everything to me before they did it and that helped. And like I said before, it did not hurt at all. Everyone was great.

67. 13. I believe they should have just women doing the inserting of the wire and the x-raying. I was disturbed at having a man tell me not to move while they reinserted the wire and took more x-rays.

68. 10. I usually bring a book and read.
12. My second wire insertion was the most painful because the area to be marked was at the back of the breast, against the rib cage. The physician had a difficult time inserting the wire. While on some level I experienced wire insertion as barbaric, I was also able to distract myself and tolerate it without difficulty.
13. Doctors might do more to prepare patients—explaining not only what will happen, but also making suggestions as to how to best tolerate it, e.g. bring a book, techniques used in Lamaze.

69. 10. I did try to distract myself by thinking about other things.
12. The physician had told me that the procedure would be very painful so I was very anxious, and then it wasn't as bad as I expected. He told me this just a few minutes before the procedure.
13. I think warning the patient is a good idea.

70. 12. My first cousin told me that she did not find it painful (she has had it done 3 times); that all you really felt was the squeezing and pulling of the breast from the mammogram. I did not know when it happened. The doctor told me that the worst was behind me and that I could go on upstairs. I said do you mean that you

have the wire in and he said yes. I wasn't thinking anything pleasant. I was scared, but I trusted [my cousin] and she said hers didn't hurt and neither did mine. It is the idea that the word wire is used, the wire is inside the needle.
13. Tell them about the procedure saying needle. Is not the wire inside the needle? It's the idea of a wire. Visually you think a wire is big—it's not. Tell them some patients say it doesn't hurt, that you don't feel the actual insertion, just the squeeze and pinching of the breast from the mammogram machine; that it is simple and quick, nothing more than having a mammogram.
O. The admissions nurse told me that some women said it hurt if you took something for pain and some women said it hurt if you didn't. My cousin was with me and heard that. She didn't like her telling me that. I took nothing. I agree with [my cousin] you should tell women that some say it doesn't hurt, you don't really feel it.

71. 10. I watched the monitor TV to see what they were doing.
12. Since it was an aid to later surgery and recommended for finding the area for biopsy, I felt it was necessary. The professionals doing it were very considerate and explained the procedure. I was not happy that it had to be done, but happily the breast biopsy was negative.
13. People have different pain levels. Dread and fear can heighten pain. Having my surgeon explain that the needle insertion would help him find the exact spot to excise helped remove the dread and fear. The local diminished the pain during the procedure.

72. [Pt. attached a page of comments about surgery, NLP, etc.; excerpts follow.]
I was told to be at the hospital at 8 a.m. and I was a few minutes early. No one acknowledged my presence, except to ask what kind of insurance I had, for 45 minutes. At 8:45 a.m. a nurse rushed in and asked, 'Hasn't anyone hooked you up to an IV or anything?' I replied, 'No, nothing.' She whisked me into a room and had me disrobe from the waist up. Then the x-ray, thank God, I got to sit down this time. Now, I'm real nervous and stressed out and undergoing considerable discomfort, trying to stay in the chair, with my breast clamped in the machine and then the needle with the wire attached is inserted. Even the thought of this makes me lightheaded. The previous time I had this done standing and I almost passed out. They had to let me lie down and get me a cold cloth before I was able to continue. Of course, we had to start all over.
My suggestion is, why can't medication be given to relax and numb the patient before this procedure begins? Even if you've never had anything like this done, you can imagine having a needle and wire inserted into unprepared flesh, and then crushed, is not ideal. Then, removing the needle, ouch! Of course this procedure was done on both occasions by a male, who couldn't possibly understand what I was experiencing. [Pt. added, re medicines]: I would have taken it if I had been offered any.

73. 10. I was unable to distract myself and remained upset throughout most of the

procedure.
12. I thought it took a long time and about 3 or 4 x-rays had to be taken and developed. I was also not allowed anyone in the room with me for support. I think this would have been helpful especially when I was left alone in the room, in the mammogram machine with needles and/or wires inserted in my breast during x-ray development. I think a sedative before the procedure should be given and I'm just glad I didn't know exactly what was going to happen.
13. Give a sedative first. Never leave patient alone. It is very distressing. I almost passed out and ammonia was used. My stomach was pinched by the x-ray being pulled out of the machine. The patient should be wheeled to the OR.

74. 10. I tried to stay relaxed as much as possible and then I just observed the procedure being done.
12. I was prepared for it physically and emotionally.
13. I remembered feeling chilly the whole time and afterwards. Maybe the room could be a little warmer.

75 10. I felt quite relaxed.

76. 12. Scared the first time, nothing the second time.
13. They make it easy no matter what.

77. 12. Anxious but not 'off the wall'! It would be great to find an alternative for women who have less tolerance for the procedure. Once the wires were in place it wasn't painful, just discomfort.
13. Nurses a lot more emotionally available. Also my personal experience involved the doctor teaching at the same time, which, although I know it's necessary, was disconcerting. How to resolve that I simply don't know.

78. 10. Talked with doctor and technician.
12. Seeing a wire stuck into my breast was disconcerting.
13. For me, the procedure was more emotionally traumatic than physically painful. Fortunately the doctor and technician were both supportive and excellent. The surgery itself was very painful.

79. 12. It upsets me still a year later to even think about it so I'm not going to write anything. I wish I had not had the experience and I won't ever go through this again.
13. I would have liked honest, detailed information (written) about the experience which I could have taken home, thought about, and decided if indeed I wanted to do this.

80. 12. Extremely unpleasant to think about so I tried not to. The set up took a very long time and was very uncomfortable. The worst thing was that the equipment broke and they had to do it again. That was no-one's fault but hellish for me,

having experienced it and then having to have it done right then all over again. Should not have happened.
13. I would say check their equipment more carefully. Through the whole long, long, long ordeal the female doctor and nurses were wonderful—talking and keeping me distracted. They were great.
O. Actually, I would prefer the needle insertion technique because it locates the lump for the surgeon and makes the surgery easier. I do think that you need to let people know the results much faster—esp. people who have had cancer. The long wait for the results of biopsies and mammogram results are far more torturing than any procedure I've ever experienced.

81. 12. Only mildly apprehensive.
13. Only an unavoidable delay on the part of the surgeon caused a longer wait before the biopsy. (The surgery before mine took longer than expected.)

82. 12. Guide wire insertion itself was not painful; the numerous mammograms taken to make the breast grid were very painful—machine needs to be redesigned—hard, cold, and hurts entire area around and below breast.
13. Pad or redesign mammography machine.

83. 12. The first insertion I was very anxious, not knowing how painful it would be. My mother died of breast cancer so I was carrying that baggage plus I work as an RN in the OR and my experience with waiting for patients to come from x-ray led me to believe it wasn't very precise. I was pleasantly surprised to find it an 'easy' procedure. I did get cold during the first one.
13. If the room is cool offer a wrap around the shoulders while waiting in the machine.

84. 12. Main reaction was curiosity as to procedure. There was a team of observers so attendant was explaining things to them, and that distracted me. Also I had had a hysterectomy in Dec. '93. I was rather numb to hospital procedures by then. It was 'no big deal!'

85. 10. I looked away. I thought about a spring day outing.
12. I was very horrified because of one reason. I kept telling the doctors over the years that I felt a lump in my breast. The form for the mammogram was lost. So it was scary because I knew I had a lump there and they wouldn't believe me because I was young.
13. Add a mild pain reliever medication before doing the procedure. Believe the patient. She knows the changes in her body. Be honest with her and help her deal with the procedure emotionally even if it means for her to talk with a counselor or social worker.

86. 12. I wanted to be sure an experienced MD would do the procedure.

87. 10. Imagery.
12. Humiliating, technical. I was embarrassed. People would open and close door to hall, passing in and out getting equipment or consulting with doctor as I sat entrapped in a machine.
13. Absolutely. I kept wondering how my doctor would feel having a female flatten his penis in a machine, then stick a needle slowly into it!

88. 10. Thinking about what was going on and the uncomfortable position I had to sit in plus pain at times.
12. First of all, the thought is frightening, second when you see the things to use and they explain to you what is going to be done it is still the same, and the pain is bad at first when you have to sit in one position with the needle inserted.
13. Make it not hurt.

89. [Pt. appended a letter of comments. Excerpts follow.]

I showed up for the insertion and was taken into a room to have it done. I spoke with Dr. F. She instructed a young male doctor and then she left. My anxiety began at that moment when I realized that he was not experienced—but I hoped for the best, that he was trained enough to do the job. He began scrutinizing my breast x-rays trying to figure out the grid system. The procedure started, wire inserted, x-ray taken, not on target, another try, x-ray taken, nothing, another try, x-ray taken, nothing! At this point I voiced some concern (mainly at the amount of x-rays taken on one breast—pain was not a major concern). He went out and returned with Dr. F. who took the wire out, inserted it and we were through. If she had done this to begin with, I would have had one x-ray, much less anxiety, and out in 15 minutes.

I was recovering as I walked to the 8th floor and was greeted by a friendly nurse who needed to insert an IV. She tried my back left wrist but my vein ballooned, so she tried my right wrist and only bruised it, so finally she went for my arm (elbow) but during the operation the blood backed up and came out on my arm. So prior to the biopsy I was a 'basket case' with a pin-cushioned x-rayed breast and three bandages on my arms from ill-gotten IV's. The biopsy was benign so I decided it was just a bad time for all. [Pt. details other difficult experiences with mammography, ultrasound, long waits, etc., then returns to subject of NLP.] I think the pain is minimal as long as one is taken in promptly and met with competent hands. The women with whom I had the pleasure of sharing the mammography waiting room for many half hours expressed the anxiety of the wait.

90. 10. Not that I can recall—I was anxious and afraid of further pain.
12. Physical. I tend to have a relatively low tolerance level for pain, therefore even shots hurt! Emotionally, I wasn't really prepared for this procedure. The only reason I went forward with the second biopsy (1st was lumpectomy on left breast) was because my mother-in-law had just died from lung cancer and my greatest concern was alleviating my husband's fears. My fears were mostly for the pain I expected to experience and actually did experience—twice since they had to

remove the wire and start over a second time.
13. Perhaps a video of the procedure to show exactly what occurs, an honest explanation that some real pain will be involved—at least compare it with having blood drawn, or having a shot of novocaine at the dentist's—something along those lines so the individual will know how to relate based on her own past experience. Let the patient know that the doctor doesn't always insert the wire in the exact location on the first attempt. I'd rather know everything to expect before I go in.

91. 10. Tried to imagine that I wasn't there.
12. Physically it was slightly uncomfortable. I felt like I wanted to pull it out. Emotionally just the whole process made me nervous.
13. Thorough and complete explanation would make the patient less anxious about what to expect.

92. 10. Deep breathing, relaxation.
12. The only real problem I had was vagal—I almost fainted. I was not aware of feeling anxious or pain (except for minor pinprick). I was unable to keep my head up and they had to do it with me lying down.
13. I think my experience was uncommon but a possible reaction.

93 10. I kept thinking it would soon be over.
12. It was something that had to be done

94. 13. A short video to show the procedure would have helped with my anxiety.

95. 12. A minor procedure, competent staff.

96. 10. Brought my law partner with me as moral support, asked lots of questions.
12. Not nearly as big a deal as when the fellow was rude, did not explain what was happening, would not answer my questions, and used anesthetic without my OK (after stating we could not use it). His response to my questions was 'hold still'. I recommend the hospital to no-one because of this man.
13. Answer questions patiently. Talk to patient throughout with running dialogue as to what is happening (and patient is unable to see), do this if patient requests it (and I did, many times).

97. 10. I was concentrating on not fainting from the pain.
12. I felt like a piece of meat on a table, like I wasn't supposed to have any feelings.
13. To prepare the person a little better. Find out if the person has a low pain reaction [threshold]; if so help them out by offering medication to make the procedure more comfortable and tolerable

98. 10. I tried to mentally minimize the pain: it's not as bad as say, childbirth, and it

will be over very soon.
12. Basically a learning experience. I have had breast reduction surgery, so there is a lot of scar tissue. This was not expected to be a problem, but when Dr. M. did the biopsy, she found the guide wire had formed a loop inside. This accounted for the extreme pain while inserting the guide wire. So next time I would have a local beforehand. The people inserting the guide wire were very reassuring. I would recommend that anyone who has had breast reduction surgery be given a local, automatically, before insertion of the wire.
O. Because the guide wire ran into unexpected scar tissue, we decided that I would grit my teeth and let them go ahead. Prior to the procedure, I did not have a local because it is expected to be as uncomfortable as the procedure itself.
13. Only what I answered in the last question: potential problems of excessive scar tissue on the inside

100. 12. No physical or emotional reaction.
13. Sorry I can't help—I had no pain, no nothing! Just one of those things some of us must go through.
O. Guess I'm a toughy.

101. 10. Pretty hard to do—I was fainting due to the intense pain.
12. I don't think I would want to do it again without some strong medication. This experience would make me hesitate to have it again.
13. I can't believe any doctor would attempt surgery after a patient has been so traumatized in the preparation for surgery.
O. I was told I would get a pain medication/relaxer by my admissions person—then to find out I wouldn't!

102. 12. The insertion was fine. I thought the mammogram, to see where the needle was, was excruciating. I've had lots of mammograms at U Va and never have I had any of them be so painful. I was bruised for weeks!
13. If they could possibly not have to smash the breast so flat and for so long.

103. 10. I thought about, when this biopsy is over, I will be OK, the results will be good.
12. I was a little nervous and anxious, expecting pain.
13. Please make sure the wire is inserted in the correct place, without pushing too hard.

104. 12. Did not upset me, just concerned

105. 12. Happy with this.
13. Shorter waiting at center.

106. 12. A little anxious. The surgery was the worst—the feeling returned before the doctor finished stitching it up.

107. 12. Just wanted to find out what problem was so it can be fixed.
13. It really wasn't that bad of an experience.

109. 10. It was hard to do.
12. I was very nervous cause I was afraid of what they might find. It's hard to relax when a sharp object is being placed in your body.
13. Figure out a way to deaden the area.

110. 12. Felt faint, became nauseated, and vomited. Almost passed out. Someone learning the procedure pushed the needle too far; the doctor teaching said so and had it pulled back.
13. My doctor did not come in until Resident had inserted needle too far, very fast and very hard. I became physically ill. Also had blood drawn just prior to procedure and they had to stick me several times and I started sweating and felt faint. Do not think they should have drawn blood until after procedure.

111. 12. Different and less pain than prior surgery.
13. Everything was fine.

112. 12. Made me feel faint and sick to my stomach.
13 A little more numbing meds., lidocaine

113 10. I always try to think of pleasant things when I think something unpleasant is about to occur or during it—like having teeth drilled.
12. I sometimes have little brief sharp pains in my breast at the site of the biopsy. I don't want to have any more mammograms especially on the tender side.
13. The experience was not sufficiently memorable for me to have any suggestions. Everyone was very kind and anxious for me to be comfortable, and they succeeded.
O. I think the part of the procedure that was most unpleasant was the use of the mammography machine. The wire insertion and biopsy procedure were not bad.

114. 13. Just keep on doing the same thing.

115. 10. Focus on picture.
12. Doctor talking another through the procedure was distracting, disturbing. thought before going through the procedure that the person doing the procedure was experienced. I did not like the fact that I was the <u>first</u> patient. I was under the assumption that another doctor (the one talking the intern through the procedure) would be doing the procedure.
13. Practice before doing this procedure. <u>Poking</u> around with needle or guide wire is uncomfortable. Avoid jiggling the wire.

116. 10. My husband came in to be with me after I started crying.

12. Physical: fine. Emotional upsetting.
13. More explanation about the procedure and more concern for patients' emotional needs, anxiety, etc.
O. Possibility of cancer was very emotionally upsetting. Breast exposure was upsetting, only local during surgery was upsetting. Other surgeries far less anxiety producing. Please note that I suffered severe anxiety that was ignored by the doctors. After a lump was found I was shown a film on breast examination that caused a panic attack. When I asked for help with my anxiety attack I was refused medicine. I was actually told by one nurse (who was trying to be helpful) to buy some wine. I have no history of drug abuse, I don't drink, and yet my obvious anxiety was not addressed by the doctors, apparently due to some misguided sense of fear of addiction or something. I lost my grandmother and my father to cancer and my mother had cancer in her twenties. My mother actually committed suicide one month after my grandmother died of cancer. She had cared for her during her illness. My anxiety was the worst part of the experience and the doctors could have made it more bearable if they had not ignored that.

117. 10. I tried—I'm a worrier and was very anxious about the procedure.
12. As above (anxious).
13. The doctors were great. They did comfort me but, like I said, I'm a worrier. Maybe if I had had a nerve pill or something mild it would have helped me. The pain wasn't bad, just my nerves! I suggest giving those who are anxious a mild sedative.
O. I would like to say, even though I am a very nervous person, I was very worried thinking the worst, like all women. The doctors, and all the staff from the time the procedure started were wonderful to me, and did all they could to make my 'visit' as pleasant as they possibly could. I think the hospital is up-to-date on all things in the medical field and want to say thanks to everyone again for helping me.

118. 12. I was told it would not be painful. It was. The worst thing about this was having the wire insertion done early morning, and then waiting all day before they did the surgery. It was awful and I will never go through it again. It was all for nothing.
13. You cannot compare this to a mammography. In my case it was more painful But the worst part was the waiting all day. I was so stressed out by the end of the day that it was the worst experience I have ever had. After it was all over I broke down and cried and cried—unlike me.

119. 10. I used denial and a good relationship with my primary care provided (also Dr. P. was great!)
12. Most of my anxiety was on the biopsy to follow, not its pluses or minuses but the 'procedure' itself. I am a wimp! Most discomfort from the 'squeeze'. Wire insertion was less [uncomfortable] relatively speaking.
13. Let them talk with folks who have 'been there'. Service available through

UVa's Body Talk, Health Information Center for patients. Have patient support one to one available.

120. 12. It was just a pinch. Dreaded it but wasn't bad
13. Explain that it really isn't very painful.

121. 10. At the time I was pregnant and concerned about the radiation exposure as well. It was difficult to think pleasantly about anything.
12. I had the following problems with this procedure. 1) As I was pregnant, I was concerned about the radiation exposure risk to the fetus, and was given inconsistent responses (one resident seemed concerned, others were reassuring), and not enough hard information until a day later when I was put in touch with a different radiologist altogether. 2) The first resident who attempted to do the procedure was unsuccessful. I am not sure she had enough experience to be successful. As far as I can recall, a second resident also attempted to assist, but ultimately a third physician (an attending, I assume, but am not sure) was called in and finally was successful. By then I had been in the mammography machine off and on for well over an hour, and had outlasted the painkillers; the final insertion was done after they wore off. Part of the original physician's difficulty, in the first instance, was my moving when startled by the sound of the machine. I could have used better preparation for what that sound would be like. And, given the difficulty with locating the areas needing wire insertion, I could have used a much more experienced physician to perform the procedure from the start. I did not appreciate being practiced on and only then handed over to someone with greater skill after initial failure.
13. 1) Give more information (and consistent information) to pregnant patients about radiation exposure risks. 2) Explain the sound of the machine (a loud report) so that patients will not be startled, jump and move, thus requiring redoing of the procedure. 3) If the areas to be located are difficult to find, have an experienced radiologist do the procedure from the start.

122. 10. Meditated.
12. At both hospitals staff seemed very sensitive to me which made me feel much less anxious during procedure. Fainted during first time. Worst part of every procedure was waiting to go into room for insertion.
13. Treat patient as adult. Make time waiting as short as possible or keep someone with patient. Offer anxiety medication.

123. 12. Was a little anxious but it was not bad.

124. O. I was given something to calm me because the blood pressure cuff was too tight and when they took the pressure it was very painful and kept making the pressure go up over and over as it went higher.
10. After they turned the blood pressure machine off and only did it once in a while I was fine. I was curious about what was being done and asked questions

once in a while and got answers.
12. I feel my emotional and physical reaction were good.
13. There are women who won't ask questions. I'm not one of them; I need to know all the procedures, what's going to happen and why so that I'm not apprehensive. Tell us all these things without being asked. Also be sure the blood pressure cuff is large enough.

125. 13. It should be done in the same area where the biopsy is to be performed so you don't have to get dressed and travel any distance.

126. 10. I prayed.
12. Everything went fine. I do not have any complaints.

127. 12. My initial reaction was negative—somewhat repulsed by the idea of a wire piercing the breast Then I simply took a positive attitude, summing up all the information I know that assists in diagnosing malignancies. Result: fear dissipates, I'm fine—the prospect of pain is tolerable, pain itself is minimized, mind triumphs over matter!
13. The doctors and nurses knew, or guessed accurately, what I was feeling and sought to comfort me. They informed me every moment what they were seeking to do. This meant the most to me and was very calming.

128. 10. I didn't know what to do. I didn't know that I was getting a wire insertion in my breast.
12. I was in the hospital for a week after this. I started having a lot of shaking and no-one knew why. I was admitted to the intensive care unit. I will never have this done again. I still have pain in my breast. I need someone to look at my breast.
13. Not to give it. My breast got infected and I wasn't given anything for this. The doctor left stitches, they got infected, I had to go back for that, still nothing for pain. And now I still have a lot of pain in my breast.
O. Was never given anything for pain. I went back to the doctors more than four times, for so much pain.

129. 10. Tried to remember I had beaten cancer in 1986 and prayed the node would not be cancer.

131. 12. I was appalled by the lack of prior explanation and preparation for this procedure. The physician appeared annoyed and hassled—apparently I took more time than she had allotted.
13. This was the most distressing medical experience I've ever had. I'm still so angry that I cannot articulate any suggestions—other than asking that doctors remember that people are not experiments.
O. The guide wire insertion was painful because of cold (both literal and figurative) environment. Follow-up care and the biopsy itself were

wonderful—professional, caring staff there. But the mammography section needs a great deal of work.

132. 12. Rather anxious on first insertion, second insertion was 'old shoe '
13. Try to assure patient that it will not hurt or cause severe pain.

133. 12. Uncomfortable but necessary.

135. 10. There was no pain but very emotionally draining.
12. I just wanted them to do whatever they needed to do so that the biopsy would have the best outcome possible.
13. Probably knowing no more than I did was best. Otherwise, it might have been very scary.

136. 12. It was quite painful and the sensation was disturbing. It took all my self-control not to vomit. They missed the questionable area in my breast and had to do it again. I would dread it if I had to have it done another time I also felt I would faint.
13. I felt the doctors I had were new and inexperienced, although they were very nice. Their inexperience was disturbing to me. I don't know how you could make this more comfortable.

137. 10. I put my trust in God, my doctor.

138. 10. I tried to relax but I was very anxious about the results.
12. Physically: I did experience pain, but they always stopped and gave me something for it. Emotionally: I was extremely anxious because of the results, but the doctors were very supportive. Dr. B. was great. She held my hand and when it was over, she even gave me her home phone number to call if I had questions or problems.
13. Nothing—they were very good about explaining the procedure and always gave me something to make the pain go away.

139. 12. I was somewhat anxious prior to the procedure but felt fairly calm immediately prior to the insertion. Most unexpected, however, was the rapid, visceral response that occurred as the needle was inserted. I felt extremely faint. It was completely out of my conscious control and several minutes elapsed before we could continue. That was the most unnerving but I was not at all troubled by the procedure after that.
13. I was worried just prior to the procedure about the possibility of fainting (it didn't even occur to me that it would happen to me) and what to do if I felt faint. That was very helpful. I was also seated prior to the procedure (and during) and was glad to have the chair under me when my blood pressure dropped.

140. 12. I was real upset. I didn't know what to expect. It wasn't as bad as I had

heard. I was afraid it was cancer. My sister just had her breast removed in May of the same year.

13. To be as nice as they were to me. The doctors and nurses were so caring.

141. 10. I was on the verge of passing out several times. A bad situation, I would not go through it again.

12. I felt the wires going in. The pain I suffered was more than when I had a major operation. Would not recommend it to anyone.

13. Patients need to be sedated!

VITA

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