

Committee on Energy and Commerce - Subcommittee on Health
Testimony of Kristen A. Zarfos, M.D, FACS
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Breast Cancer Patient Protection Act -

Good morning Congressmen Pallone and Green, along with the entire subcommittee on Health of the Energy and Commerce Committee. It is honor to come before you to share information on one aspect of breast cancer care of women and their families in America today .

My name is Dr. Kristen Zarfos, fellow in the American College of Surgeons,. I am a general surgeon with a focus in breast cancer care. I am an assistant professor of surgery at the University of Connecticut School of Medicine, as well as Director of the St. Francis Comprehensive Breast Health Center in Hartford, Connecticut.

Background:

Until 1985 almost all women who were diagnosed with breast cancer underwent a surgical procedure called a mastectomy. It is likely that someone in your family has had this procedure. It is a 2 hour operation, usually under general anesthesia where all of the breast is dissected off the chest wall, removing most of the overlying skin and approximately half of the lymph nodes under the adjacent arm. As you might know, or at least expect, it is painful, accompanied by nausea many times, compounded by the need for rubber tubes to drain blood from under the remaining skin. It is deforming and comes under the shroud of a woman facing a potentially life threatening disease, possible chemotherapy, radiation therapy and uppermost in her mind -- the fear of the impact on her children and husband.

The good news is that federally funded prospective clinical research showed in 1985 that not all women with breast cancer need have a mastectomy, but could have a lumpectomy with radiation therapy. The even better news is that each year since the early 1990's, because of early detection, fewer American women have mastectomies each year. Yet each year, more women are diagnosed with breast cancer -- now over 200,000 each year. And still, because of certain individual characteristics (which I would be glad to share with you in more detail if you wish) approximately 125,000 American women require mastectomies to give them the best possible chance that the cancer will not recur.

Until 1996, the average hospital stay for a mastectomy, based on data collected by a hospital association, was 2 - 4 days. This hospitalization was for the basic health care needs of pain control, nausea control for the needed pain medication, management of the necessary tubes draining blood from the chest wall, overcoming the effects of anesthesia, and nurses teaching the patient, after she is awake, and her caregivers how to dress the wounds and handle the drains. Rarely were infections seen in the mastectomy incisions. Even more rare was a patient seen returning to the emergency room with a problem or being readmitted. In fact, in the 20 years of my practice, I have never had a patient of my own or the surgeons who I covered return for these needs.

In 1996, exclusively patients paying for private health care insurance were suddenly being told that they would have to leave the hospital a few hours after their mastectomy -- regardless of any underlying complex medical problems they might have, such as diabetes requiring close monitoring and adjustment of insulin shots because of the stress of surgery, severe heart disease, or being on blood thinning medication. Under no consideration was if the patient had a prior history of adverse reactions to anesthesia, post operative pain that oral medications would not control, how far they needed to travel home still groggy, in pain and nauseated , or if they even had an adult to care for them at home. This unilateral decision on the part of several health care insurance companies was made without any prospective clinical research showing it was safe.

As the Commerce Committee, you should be aware that , as consumers earlier, in the year, before knowing they would have to face breast cancer, women had purchased health care insurance policies based on the reputation and the track record of what services the company provided. These consumers paid for

and assumed they would receive what basic care they had contracted for during the time period of that contract.

In mid 1996, without informing the patient, i.e. the insurance customer, the several insurance companies changed the provision of their contracts. Thus, women with newly diagnosed breast cancer, who had previously known other women who were admitted for 2 - 4 days after a mastectomy, now were shocked to be denied even 24 hours in the hospital, despite the contracted services they were still paying for. They were facing a breach of contract for services that they now so badly needed.

Imagine first being told that you have breast cancer, and all that conjures in your mind. Next you are told you would lose your breast, and the impact that has on you. Then you are told that you could not stay in the hospital but for a few hours after losing your breast. To be certain, fighting a consumer issue would not be the foremost thought on your mind. The questions that women ask when faced with breast cancer are, "Am I going to die?" (over 40,000 women die each year in the US from breast cancer); "Am I going to leave my children?"; "How painful and deforming will the surgery be?"; "Will I be able to return to taking care of my family or working?"

This denial of care was faced primarily by women paying for private insurance. Government data showed that women with Medicare or Medicaid or no insurance at all, were given the length of hospitalization after a mastectomy they needed.

Following the precedent Congress set in the mid 1990's of legislation to prevent mothers and newborns from being discharged prematurely a few hours after delivery (know as the Drive Through Delivery legislation), your colleague, U.S Congresswoman Rosa DeLauro introduced the Breast Cancer Patient Protection Act in 1997 and annually thereafter. This legislation does not mandate hospitalization, but instead restores the right for a woman and her doctor to choose whether she be hospitalized 24 - 48 hours if she needs; hospitalization she has paid for through premiums for basic health care. Without protective legislation, women and their spouses will continue to pay double digit increasing health insurance premiums, yet be denied basic - not embellished, superfluous or elective -- health care at a time of the crisis of being told the diagnosis of breast cancer. There is consensus that pain control, alleviation of the physical act of vomiting against a painful chest wall, control of rubber tubes draining blood from a fresh surgical area fit the definition of basic health care. Women who have had adverse consequences from being sent home a few hours after their mastectomies ask what have they paid insurance premiums for if their basic physical needs were not covered.

Please do not rely on what I am telling you, but refer to the many testimonies gathered on the Lifetime TV on-line petition of 20 million people, in which many women tell their own stories of being sent home within a few hours of their surgery. What they tell makes even me, a seasoned surgeon of two decades of practice, cringe at the consequences they endured. (A condensed list of testimonies is provided.)

In 1997, 20 states responded to this issue by passing legislation in various forms -- some truly protective, others just token -- as you will hear. Yet, American women in 30 states and many in the 20 states where there are ineffective laws face what has been coined as "drive through mastectomies". 65% of the 125,000 women having mastectomies across America today leave the hospital within a few hours of their surgery, regardless of their physical health needs. Remember that nobody wants to be in a hospital at all. Even the most determined patients I have had who preoperatively request going home the same day, after having surgery have requested staying at least 24 hours. Many women have the resources and they choose to go home the same day of their mastectomy. They have the right to do so. And, so shouldn't women who postoperatively have the physical needs requiring hospitalization should have the same right to receive the care they need and have paid for.

But, let me pause here to clarify that this is not solely a woman's issue. This is a family issue. 125,000 American families face this each year. Approximately 975,000 -- nearly 1 million families have faced this

over the last decade since this practice started. This is a family issue, which I am sure many of you may have experienced; as husbands or sons hearing this information today, you may be thinking what it would be like for you to take care of your wife or mother in pain and frightened. The entire family -- husbands, young children, elderly parents -- have become caregivers, most often with no previous medical experience.

These are the background facts. Following is the most important perspective from women with breast cancer who had outpatient mastectomies. These American voices from across the country will tell you what happened to them with the treatment -- or lack thereof -- of their breast cancer.

The Reality from the Patients' Experience:

Today in this audience is Alva from North Carolina. Alva came to Congress to share her story at a press conference to announce the introduction of the Breast Cancer Protection Act in 2006. Alva has asked me to share her and her husband's story in her words to help you understand the real impact of being sent home a few hours after a woman loses her breast.

Alva was 65 at the time of her diagnosis of breast cancer. Her health care insurance was covered by her husband's insurance along with their contribution. Her insurance company mandated that she have a surgeon who performed her surgery in an outpatient facility one hour away by back roads from her home. Alva was sent home directly from the recovery room a few hours after her surgery, still groggy from the general anesthesia. She was given pain and nausea medication to take by mouth, neither of which worked. She vomited, causing more pain in her chest wall, and of course preventing the pain medication from being absorbed. Her husband, a washer-dryer technician, with no prior medical experience, was her caregiver. She developed a Staphylococcal infection, causing her mastectomy incision to pull apart, and drain. The open wound required weeks and weeks of antibiotics, dressings and packings, which delayed her much needed chemotherapy for 6 weeks.

Alva was so moved by her diagnosis that she has embraced helping other women diagnosed with breast cancer in many ways. Through her advocacy, she has met two other women who underwent outpatient mastectomies in her state, despite the fact that North Carolina has a state law to prevent this. One woman is a widow in her 40's with 3 children she is raising by herself. She went home to be taken care of by her eldest son who is 10 years old, being the only person to help her with bandages and the draining tubes. As a city employee, her employer was not self-insured, so that even ERISA was not an excuse for her being sent home a few hours after her surgery. A third woman who Alva met has insurance with a very well respected company. She, too, was denied hospitalization the day of her surgery.

In Alva's words, "No person should be treated like an animal; even my Cocker Spaniel with breast cancer was kept overnight when she had surgery"

Let me share yet more personal stories from women across the country -- all of which have the common themes of pain, intractable vomiting, infection (something rarely seen before outpatient mastectomies), emergency room visits shortly after surgery, re-hospitalizations and even a fatal postoperative heart attack at home. These are included in the supplement to my testimony taken from the on-line petition. I will stratify those from the states which already have laws, with additional compelling reports.

But first, I must again tell you that despite my being immersed in this issue day in and day out for two decades, I am still shocked at what is going on outside Connecticut. I was called by a woman in New Hampshire just 6 weeks ago. She is a woman in her 50's, partially paralyzed and on blood thinning

medication for blood clots, who was told she would have to go home a few hours after her surgery. Her paralysis limits her mobility; managing the blood thinners can be tricky to prevent her from hemorrhaging. The thought she would be unilaterally denied hospitalization says that each woman in this country needs to be treated individually, not as a faceless procedure.

Refer to the provided supplement: 1. Testimonies from women in states with legislation, 2. Additional testimonies from across the country.

These are facts from the people who matter -- American women and their families across the country and in ever increasing numbers. What they say is the reality. This is a major obstacle to the treatment of 125,000 women with breast cancer each year.

The purpose of the Breast Cancer Patient Protection Act is simple and straightforward:

#1 To restore consumer services of basic health care that women have paid for, but is being withheld.

#2 To restore a right to the basic health care of a choice of the services of a 24 - 48 hour hospitalization. This is not a mandate for hospitalization, but rather quite the contrary, a restoration of the individual patient's rights based on her physical needs for care she has paid for.

#3 To provide uniform protection to all American women and their families across the country rather than the current disparity in the care of women with breast cancer in the United States.

Shouldn't all American women and their families have the right to having basic health care they have paid for the day they face mastectomy?

I believe, as do most Americans, that our legislators have served the consumer rights and health protection rights of the American people when we have brought issues to your attention, as with the Drive-Through Delivery legislation. We turn to you to do as you have before to help American families faced with breast cancer in a way that brings no additional cost to the American taxpayer, and adds no burden to health care premiums, as the services of basic health care the patient has already paid for.

We turn to you to help us. Pass the Breast Cancer Patient Protection Act.

Thank you.