

# **Reducing Delay in the Detection and Treatment of Breast Cancer**

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Most breast cancer death can be ascribed to simple delay in cancer detection and treatment. Simply reminding patients of their upcoming screening exams, and tracking of patients with signs suggestive of cancer, has the potential for leading to enormous reduction breast cancer death. Indeed, the telephone is our most powerful tool for reducing the lethal burden of breast cancer.

Most breast cancer death is the result of delay in cancer detection and treatment. We shall examine the scientific basis for this surprising fact in a minute, but the central finding of a decade of research carried out by my group has been that simply reminding patients of their upcoming screening exams, and tracking of patients with signs suggestive of cancer, has the potential for leading to enormous reduction breast cancer death.

### **Delay in the Treatment of Breast Cancer**

Delay in the treatment of women with signs suggestive of breast cancer has been found to occur between the time of the first symptom until the time to the time of treatment<sup>1</sup>, from the time from the first symptom until the time of presentation to the physician (“patient delay”)<sup>2,3,4</sup>, from the time from the first presentation to appearance at the hospital (“GP delay”)<sup>5</sup>, and from the time of entry into the medical system until the time of treatment (“hospital delay”)<sup>6-12</sup>. We have recently developed a new method for determining the lethal consequences of such delay. While the mathematical details, and quantitative findings, of this method will soon be published, the general lesson is clear: delay in the treatment of breast cancer results in a considerable increase in the breast carcinoma death rate. Furthermore, it has long been apparent from many studies that such delay, and its lethal consequence, is not widely distributed among the population of women with breast carcinoma as a whole, most of whom are treated promptly, but in a small fraction of women who have “fallen through the cracks” and experienced very long periods of delay, often of many months duration<sup>1-12</sup>.

Delay in the treatment of breast carcinoma is also the most frequently filed, and second most expensive (after neurologically impaired newborns) malpractice category<sup>13,14</sup>. Thus, delay in the treatment of breast cancer is a failure of our medical system that hurts both the patient and the physician. Curiously, analysis of such lawsuits indicates that they are seldom the result of medical error *per se*, but are usually the result of the simple, and all too familiar, difficulty of

keeping track of patients<sup>13,14</sup>. One recent study found that “PCPs did not feel personally responsible for one-third of patients recently seen”.<sup>15</sup> Only 15-20% of physicians and 20-25% of hospitals have electronic medical record systems<sup>16</sup>. Even when used, these systems are seldom optimized for preventative medicine and patient tracking, and, in fact, have been found to make “tracking and monitoring of preventive health and chronic illness unwieldy and offered little or no improvement when compared with paper charts”.<sup>17</sup> Much patient care is fragmented, and many patients move from one physician to another, at one institution and another, with far too little exchange of information. Clearly, better tools for tracking patients would reduce much of the burden of delay-associated lethality.

### **Delay in the Breast Cancer Screening**

Delay is also a widespread feature of cancer screening. At our institution, the Massachusetts General Hospital, only 6% of the women who had a screening mammogram 1992 utilized all 10 mammograms possible over the next ten years, while the mean number of mammograms utilized was 5.06<sup>18</sup>. Similar findings have been made by Yood et al<sup>19</sup>, who studied mammography attendance among women at the largest HMO in Michigan and by Sobogal et al<sup>20</sup>, who studied usage patterns amongst Californians receiving Medicare between 1992-1998. Phillips et al<sup>21</sup>, using several sources of data, found that while 70% of women age 50-74 have had at least one mammogram, only 16% have utilized annual screening. Even lower levels of long-term screening use and promptness have been found among traditionally underserved women as defined by race, ethnicity, and socioeconomic status<sup>18,22</sup>.

Curiously, women do not delay beginning screening. Here at our institution, the median age of first mammogram is 40.4 years; 60% of women have their first mammogram by the end of their 40th year, and almost 90% have begun screening by age 50.<sup>23</sup> National telephone survey data has revealed that by 1997 approximately 80% of women age 40-49 and approximately 90%

of women age 50-69 reported having had at least one mammogram.<sup>24</sup> The difficult is not in convincing women to begin screening; rather it is in convincing them to come back, and on time!

What are the negative consequences of the failure of most women to return on time for annual screening examinations? To answer this question, we developed a computer simulation modeling of breast cancer growth, spread, and detection<sup>25,26,27</sup>, based on quantitative estimates of the relative size at which invasive cancer is detected by screening versus in its absence<sup>28</sup>, the rate of tumor growth<sup>29</sup>, and the relationship between tumor size and survival<sup>30</sup>. This computer model could tell us the impact of various screening intervals on the breast carcinoma death rate. The results of the model told us that each year of delay degrades the life sparing potential of screening by about a third. Similar results have been found with a Markov model of screening<sup>31</sup>, and from the analysis of the sizes of cancer found among women who took advantage of various amounts of screening.<sup>18</sup> The benefit of prompt annual screening is also suggested by the finding that while the appearance of larger palpable tumors is reduced in the year after a negative mammogram, they begin to accumulate at a regular rate from about one year onward<sup>32</sup>. Once a year has passed, women who have not returned for screening are right back in the risk groups with women who have never attended a screening exam!

We also examined the relationship between the regularity of attendance at screening, and the occurrence of false positive results leading to biopsies; most such false positive occurred in women who came in intermittently, probably because of the absence of recent mammograms that might have ruled out the biopsy.<sup>33</sup> So, attending screening more frequently and regularly not only greatly reduces the risk of breast cancer death, it also leads to the counter-intuitive outcome of *fewer* false positive positives!

### **A tool for improving screening utilization: Computer-generated reminders**

Why do so many women fail to return promptly for their annual breast cancer screening exams? The simple answer is that women are seldom provided with effective reminders to help

them remember to make and keep mammography appointments. In one recent survey in Wisconsin, 60% of women over 40 could recall having received a dental reminder over the last year, and 70% a reminder for a veterinary appointment, but only 9% could recall having received a reminder for a mammogram<sup>34</sup>.

If forgetting is an important mechanism behind much of the failure to make and keep mammography appointments, then might simple reminding improve the use of screening? More than a hundred studies have shown that postal and telephone reminders enhance the likelihood of attendance at mammography exams<sup>35-47</sup>. Indeed, aggressive use of all types of reminders is common in dentistry, where the rate of no-shows is typically less than 10%<sup>48-52</sup>. Reminders are an unglamorous, neglected, expensive, time-consuming, and tedious aspect of cancer screening, and are frequently ineffective. Most screening centers make their calls during the day, while many women are not home until the evening, especially women who are employed. At our institution, reminder messages are not made on Sundays and the rate of no-shows is twice as high on Mondays as on other days of the week. Screening centers also seldom have individuals who can deliver messages in Spanish or Chinese. Two clerks spend 3 to 6 hours each day making reminder calls, and yet there remains a 10-30% no-show rate. Similarly high no-show rates have reported at other institutions as well<sup>53,54</sup>. There are no special systems for identifying women who have missed appointments, nor for women who have not made appointments, so that they can be scheduled for a visit.

However, there is an effective and economical solution to the problem of reminders: computer telephony. The technology of computer telephony has become remarkably sophisticated in the last few years, with the development of powerful new computer languages, voice recognition tools, and text-to-speech synthesizers. The standard in the industry is Amtrak's talking computer, "Julie" (800-872-7245); interested readers are encouraged to call it to get some idea of the remarkable ease and power of current technology. Computer generated reminders have been found to greatly increase immunization compliance<sup>55</sup>, and have also been widely used

in general medical practices<sup>56-59</sup>. And, US Census data tells us that 98% of US families, and 95% of US families below the poverty level, have telephones.

Despite this potential of computer telephony to reduce delay in appearance at screening, there had yet to be a system designed for the specific requirements of mammographic screening centers. For this reason, over the last few years, we have developed just such a system, which provides computer-generated telephone reminder messages for women to make, and then attend, mammography screening appointments. The system uses web forms, which can be used by screening centers to enter requests for reminders to be sent to their patients. The system is on a server outside of an individual hospital, and thus can be accessed through the web from anywhere. This makes it possible to follow a woman wherever she seeks medical care. It is fully secure and HIPAA compliant. As the system uses web-forms, accessible from common browsers, it requires no special software to be installed on the screening center's computers. Furthermore, as the computer-generated telephone reminder messages originate from our server, no special telephony equipment or dedicated telephone lines are required by the screening center. All that is needed is access to the Internet. The system also has a variety of web-forms for tracking patients with signs suggestive of breast cancer, so as to reduce this aspect of delay as well.

Over the next few months, we shall be carrying out a test of our reminder/tracking system in Massachusetts. Should it work as expected, the goal is to make it as widely available as possible. But, in the meantime, we can all contribute to the reduction in death by simple attention to encouraging all women to attend screening regularly, as well as attention to tracking women with signs suggestive of breast cancer. The telephone may be our most powerful tool for reducing the lethal burden of breast cancer!

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