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Understanding Breast Cancer Rates

Scientists use breast cancer rates to monitor changes over time and to help interpret sources of risk. But cancer rates are not nearly as straightforward as they appear. Depending on the context, cancer statistics can take on many forms ranging from a simple count of new cases or deaths to more involved rates adjusted for age or other factors. Recent changes in the way that rates are calculated present further challenges to the interpretation of cancer rates. These changes improve the ability to compare current rates from region to region but have made it difficult to directly compare current rates with rates from previous time periods. These distinctions can be subtle, but understanding them is essential to the understanding of cancer rates. This fact sheet provides an overview of these and other important issues related to the calculation and comparison of cancer rates with a special emphasis on New York State (NY State).

Program on Breast Cancer and Environmental Risk Factors (BCERF)

College of Veterinary Medicine
Cornell University
Box 31
Ithaca, NY 14853-6401

Telephone: 607 254-2893
Fax: 607 254-4730
Email: breastcancer@cornell.edu
Web: <http://envirocancer.cornell.edu>

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IMPORTANCE OF RATES

Comparing cancer rates can yield important discoveries

Cancer rates may be the single most important tool for epidemiologists looking to identify causes of disease or sources of risk. Comparing rates from region to region and group to group can reveal important differences and lead to major discoveries. Scientists and others have employed rate comparisons in their search for causes for centuries. The 17th century Italian physician, Bernardino Ramazzini, for example, found higher rates of breast cancer among nuns and speculated that not having children could be the cause. Epidemiologists in the 1970s analyzed breast cancer rates in seven areas of the world and discovered a strong correlation between risk and age at first pregnancy (1). In the 1990s, researchers also employed rate comparisons to identify reductions in risk associated with physical exercise (2).

SOURCES OF DATA

National and State Registries collect and provide access to cancer data

NATIONALLY: The National Cancer Act of 1971 directed the National Cancer Institute to “collect, analyze and disseminate all data useful in the prevention, diagnosis and treatment of cancer” (3). This led to the establishment of the Surveillance, Epidemiology, and End Results program, known as “SEER.” SEER currently collects cancer incidence and survival data from population-based cancer registries and three supplemental registries nationwide. Overall, SEER registries cover approximately 26 percent of the United States (US) population.

STATES AND REGIONAL: With the help of the National Program of Cancer Registries, administered by the Centers for Disease Control, regional and state registries complement SEER’s collection efforts and bring the total US population coverage to 100 percent. The NY State Cancer Registry is among the oldest in the country and has collected cancer data for more than sixty years (although New York City was not included in the data collection until 1973). The Cancer Registry considers the year 1976 to be the first year complete enough for use in the analysis of statewide cancer trends. Reports representing approximately 92,000 new tumors are filed with the NY State Cancer Registry per year.

Data collection and processing takes at least two years

It takes the state and federal registries at least two years to finalize collection and processing of a year’s worth of data. As a result, collection and processing of data in 2000 did not get completed until the end of 2002. Publication of the results occurred in 2003.

TYPES OF RATES

Incidence and mortality rates convey different information

A mortality rate is the number of deaths from a specific cause in a specific population over a given period of time (usually per year, averaged over five years) per unit of the population (usually per 100,000). In NY State, for example, the NY State Cancer Registry reports an average annual breast cancer mortality rate for women of 30.0 deaths per 100,000 women for the years 1996-2000.

Table 1: Breast Cancer Incidence and Mortality Rates*

	NY State	US
Incidence	131.2	131.7
Mortality	30.0	27.7

**Average annual rates (1996-2000) for invasive breast cancer, age-adjusted to 2000 standard population. Rates are per 100,000 women.*

Source: ACS (2004)

An incidence rate is the number of new cases of a particular disease diagnosed in a specific population over a given period of time. Similar to mortality rates, the convention is to report an annual rate per 100,000 people based on a five year average. The most recent breast cancer incidence rate for NY State is 131.2 cases per 100,000 per year for the years 1996-2000.

Incidence and mortality rates follow distinctly different patterns

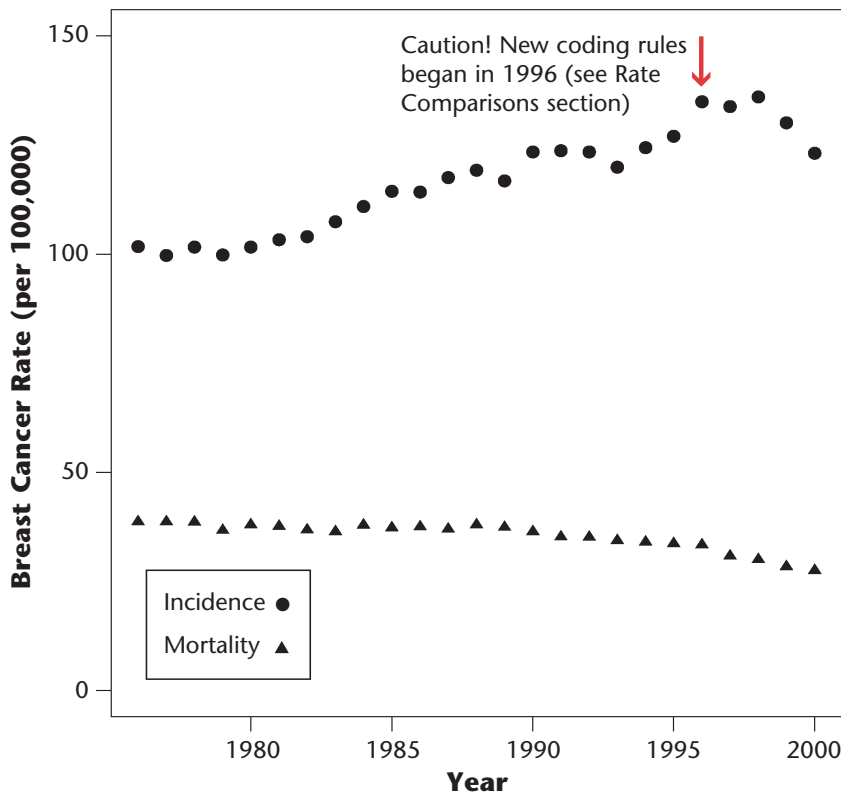
Although breast cancer incidence rates nationally and in NY State have been steadily increasing since the 1970s, mortality rates for this disease have remained relatively steady with a slight decline in the 1990s. The difference in patterns reveal differences in the underlying factors that influence incidence and mortality rates. While

incidence rates reflect risk and can be linked to many factors, including environmental and genetic factors, mortality rates for less fatal cancers like breast cancer may reflect not only environmental and genetic risk but also differences in access to health care and treatment practices. Therefore, improvements in diagnosis and treatments have offset increased incidence rates and led to a relatively steady, or slightly declining, breast cancer mortality rate.

are used to estimate the expected incidence. Age and population size are also taken into account because you would expect to see more people develop cancer in a ZIP Code with a larger population or a higher percentage of older residents. This process is called age adjustment" (4) (*note: see below for more on age adjustment*).

This expected incidence is not a prediction of future rates, but rather a hypothetical rate that can be statistically compared with actual observed rates. Higher observed incidence than expected incidence would be reason for concern.

Figure 1. Breast Cancer Incidence and Mortality Trends in NY State (1976-2000)



Source: NYSDOH. Incidence data are provisional, January 2003. Rates are age-adjusted to the 2000 US standard population. Rates are per 100,000 women. <http://www.health.state.ny.us/nysdoh/cancer/nyscr/table2/tb2breastnys.htm>

“Expected incidence” may not refer to predictions of future rates

Sometimes the term “expected incidence” is used. According to the NY State Department of Health, “expected incidence is the number of people in a given ZIP Code that would be expected to develop cancer within a five-year period if the ZIP Code had the same rate of cancer as the State as a whole. The cancer rate for the entire state and the number of people in a ZIP Code

Breast cancer rates usually refer to the more advanced, invasive, breast cancer

In situ and invasive tumors are two very different types of cancer. *In situ*, or benign tumors remain confined to the ducts of the breast and have not spread to the surrounding breast tissue or other parts of the body. Invasive, or malignant tumors are made up of cancer cells that have started to break through the duct and invade the surrounding breast tissue. While cancer registries often collect data on both types of cancer unless otherwise specified, breast cancer rates generally refer to invasive breast cancer.

AGE-ADJUSTMENT

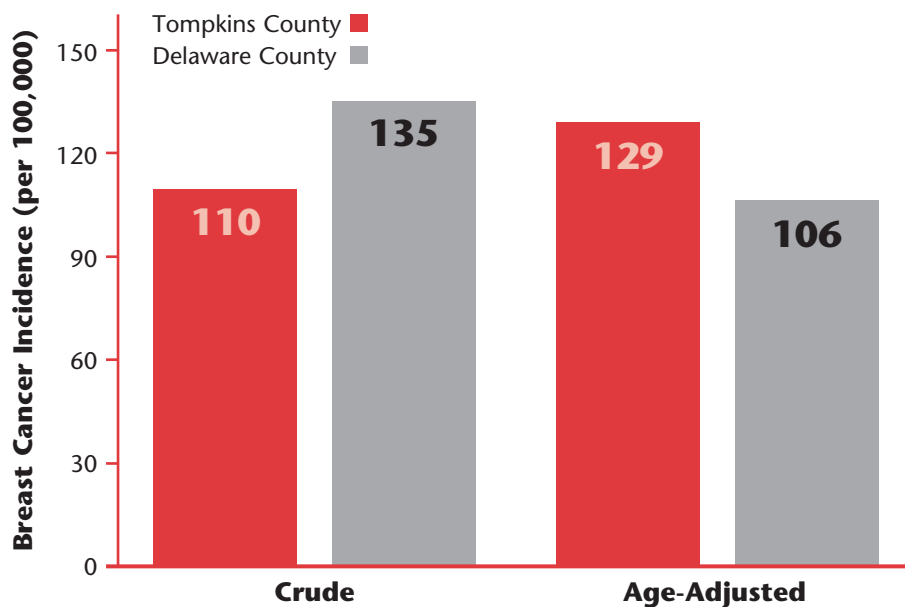
Age adjustment enables regional comparisons

Crude rates, which are simply the number of cases divided by the total population at risk, can be deceptive. High or low rates in a particular region may simply reflect differences in the age patterns of the population. A community with a higher proportion of older individuals will likely

have a higher rate of breast cancer than one with a younger population.

In NY State, for example, Delaware County (with the second oldest population in NY) has a significantly higher crude breast cancer rate than Tompkins County (with the youngest population in NY State). The crude rates, however, disguise the fact that Delaware County has a greater proportion of older women, those at the highest risk of breast cancer. Age-adjusted rates reflect these

Figure 2. Crude and Age-adjusted Breast Cancer Incidence Rates for Tompkins County and Delaware County*



* Average annual rates (1996-2000) for invasive breast cancer. The age-adjusted rates were adjusted to the 2000 standard population. Rates are per 100,000 women.

Source: NYSDOH (2000).

<http://www.health.state.ny.us/nysdoh/cancer/nyscr/vol1/v1ctompkins.htm>

<http://www.health.state.ny.us/nysdoh/cancer/nyscr/vol1/v1cdelaware.htm>

<http://www.health.state.ny.us/nysdoh/cancer/nyscr/appendix/countypop.htm>

differences and reveal that Tompkins County actually has a higher breast cancer rate. In most cases, age-adjusted cancer rates are used rather than crude rates.

Nationally, new standards for age-adjustment resulted in big differences in rates

In 1998, the US Department of Health and Human Services adopted new age-adjustment guidelines that account for the fact that Americans are living longer than ever before. For nearly 30 years, the federal government had used the US population from the 1970 census as its standard for age-adjustment. In 1998 the government recommended switching over to the 2000 census as its standard population for age-adjustment (5). Although the 2000 standard more accurately reflects today's US population, rates using this new standard cannot be directly compared with

AGE-ADJUSTMENT:

The Details

In order to ensure comparability from region to region, 'weights' are applied in the calculation of age-adjusted breast cancer rates. These weights, referred to as the "US standard population" weights, reflect the relative proportions of people in predetermined age categories in the US in a particular year. For nearly 30 years, these weights were based on the structure of the US population in 1970. Naturally, the age distribution of the US population has changed significantly since 1970 and in 1998 the US Department of Health and Human Services recommended replacing the

1970 standard population with the 2000 standard population.

This change has significant ramifications with respect to the interpretation of breast cancer rates. Since Americans are living longer, the 2000 US standard population gives more weight to older age categories. For example, the oldest age category, 85 and up, received a weight of 0.0074 in 1970, while in 2000 this weight more than doubled to 0.017. In most cases, these changes have led to what appears to be an increase in age-adjusted breast cancer rates. For example, in older publications the NY State

Department of Health reports an average annual breast cancer incidence rate for Nassau County (averaged 1986-1990) of 112.8 cases per 100,000. Currently, it reports a rate for the same time period in the same county of 136.0 cases per 100,000. These values, 112.8 and 136.0, are based on the same number of actual cases, the only change is in how they were age-adjusted. The new standard gives the appearance of a large increase in breast cancer rates, but since the new standard is applied nationwide, relative differences from region to region remain reasonably similar.

Table 2. Example of Breast Cancer Rates Using Old and New Standards in Nassau County, NY

Standard	Breast Cancer Rate*
Old Standard (Based on the 1970 US standard population)	115.4
New Standard (Based on the 2000 US standard population)	136.5

* Average annual rates (1987-1991) for invasive breast cancer, age-adjusted to 2000 standard population. Rates are per 100,000 women.

Source: NYSDOH (2000).
<http://www.health.state.ny.us/nysdoh/cancer/nyscr/vol3/v3ifemalesnassau.htm>

rates using the 1970 standard (6). Specifically, the new standards for age-adjustment calculations have led to what appears to be a large increase in breast cancer rates when compared to rates calculated using the old standard.

Most agencies and publications have successfully made the switch to the 2000 standard population making rate comparisons significantly more straightforward. When comparing rates, users should ensure that the rates use the same standard. The standard used in a calculation should be identified in a footnote or somewhere in the text as either the “1970 US standard population” (the old standard) or the “2000 US standard population” (the new standard).

Age- or race-specific rates can reveal clues about sources of risk

While age-adjusted breast cancer rates portray overall patterns, calculating age- or race-specific rates can uncover important deviations from the overall pattern. For example, the SEER cancer statistics show that while breast cancer incidence overall has been increasing for more than a decade, there is an important division with respect to age. Women under 50 had an average annual decline in incidence of 0.3 percent whereas women 50 years and over saw an overall increase in incidence of 0.6 percent between 1986 and 2001(7). Race-specific breakdowns can also reveal important distinctions. For example, while black women are 19 percent less likely to develop invasive breast cancer than white women, they

Table 3. Breast Cancer Rates for Black and White Women*

Population	Incidence	Mortality
Black Females	112.6	35.9
White Females	134.1	27.2

* Average annual incidence and mortality rates (1996-2000) for breast cancer, age-adjusted to 2000 US standard population.

Source: NAACR (2003).

are 32 percent more likely to die from breast cancer (8). It has been hypothesized that this discrepancy may be attributable to differences in health care access and quality. For more information on breast cancer risk and racial/ethnic differences see BCERF Fact Sheet # 47, *Breast Cancer in Women from Difference Racial/Ethnic Groups*.

Cancer rates are not usually adjusted for race, socioeconomics or other factors

While age is a strong and relatively well-documented risk factor for cancer, other risk factors are less well understood. Adjusting for factors such as race, socioeconomics or fertility rates can complicate comparisons and add significant uncertainty to rates. Therefore, in many instances, published breast cancer incidence and mortality rates have not been adjusted for factors other than age. This is an important consideration when interpreting rate differences from region to region in maps or other contexts. In some cases, regional differences could be due to differences in the racial makeup of the communities or differences in socioeconomics. These differences may also be due to other, more specific, risk factors such as breastfeeding practices or fertility patterns.

RATE COMPARISONS

New coding standards led to a small spike in breast cancer rates

In 1996, NY State changed the way that breast cancer cases are counted in order to improve comparability with rates nationwide. Prior to 1996, NY State counted only one tumor per cancer site per person per lifetime.

Therefore, a woman who developed breast cancer in both breasts would still be counted as just one case. In order to be consistent with SEER coding rules, beginning with 1996 data, NY State began counting a second tumor in the same person in the same primary cancer site (e.g., the breast) as an additional “new” cancer case. As a result of these changes, cancer rates in NY State since 1996 can now be compared with rates based on SEER data and most other states. Rates prior to 1996 are not directly comparable.

These changes improved overall comparability, but readers should be aware that they resulted in what appears to be a spike in breast cancer incidence rates in 1996 (see Figure 1). The new cancer cases discussed above were included in incidence data beginning in 1996 and led to a small increase in incidence rates. Based on SEER data, about five percent of breast cancers are second primary cancers among women previously diagnosed with breast cancer.

NY State cancer rates since 1996 can now be directly compared with national rates and rates from other states. NY State rates prior to 1996 cannot be directly compared.

GEOGRAPHY, MAPS AND CANCER RATES

Geographic differences in rates are not always indicators of environmental risk

Mapping disease rates has become an important epidemiological tool. Geographical variations in breast cancer rates can provide significant clues to causes of the disease or sources of risk. But the pervasive use of maps also presents challenges in the interpretation and comparability of rates from region to region. Often maps are presented with no indication of the (often substantial) uncertainty associated with estimated rates. In addition, maps in which a geographical region such as a state or county is shown in a single color representing the rate of disease in that region give the false impression that every point in that region has the same rate. This can mask what is often considerable variability. The importance of maps as a research tool far outweighs the complications, but issues of uncertainty should be considered. For more information on cancer mapping see the BCERF newsletter, *The Ribbon*, Volume 7, Number 1, and Volume 8, Number 1.

Rates in areas with low population are less reliable

In general, reliability of an estimated cancer rate is determined by population size and by the rarity of the disease. The smaller the population and the more uncommon the disease, the less reliable the rate. National disease rates can be considered relatively more reliable than those for states. States are generally more reliable than rates by county or ZIP Code, particularly if those counties or ZIP Codes have few people.

Researchers often deal with unreliable rates in maps by “graying” out questionable areas. For example, the National Cancer Institute, in maps of cancer mortality, deems county-based cancer mortality rates based on fewer than six deaths “unstable” and denotes these areas on maps using gray color. Similarly, the NY State Department of Health uses gray to denote “very sparse data.”

Reliability is often further addressed by identifying rates that are “statistically significantly” higher or lower than expected. In areas with statistically significant rates, the relatively higher (or lower) cancer rates are not likely due to chance. Therefore, data underlying the rate estimates in these areas are relatively more reliable.

Use ZIP Code maps with caution

ZIP Code maps of breast cancer incidence rates portray a more detailed picture of breast cancer rates than statewide or county maps. As a result, these maps and other high resolution maps, such as those by Census block group, can reveal more localized patterns and identify areas for further investigation.

ZIP Code maps of breast cancer rates are also less statistically reliable than county-based maps and need to be used with caution. Most importantly, rate calculations at the ZIP Code level generally rely on smaller numbers of people and fewer cases and, therefore, can be more easily prejudiced. A very small number of additional cases can lead to a significantly different incidence rate that may not reflect actual trends.

Migration complicates the calculation of rates

A mobile population presents an important challenge in the interpretation of regional differences in cancer rates. Many people do not live in the same county, state or even country for their entire lives, but their breast cancer will be registered in the state in which they were diagnosed. There is speculation that unique migration

patterns such as the influx of women with a high-risk profile into communities such as Marin County, CA or Long Island, NY may be at least partly responsible for excess breast cancer risk in these communities (9). On the other hand, research on international migration has shown that migrants' cancer risk and the risk to successive generations begins to approximate the risk in the adopted country (10). Precisely how migration affects rates is unknown but these issues must be considered when comparing regional breast cancer rates.

Conclusions

Although the examination of patterns in breast cancer rates can uncover important clues to causes of the disease or sources of risk, cancer rates must be used with caution. Spikes in breast cancer incidence or dramatic geographic differences may be due to differences in data collection or differences in the way the rates were calculated rather than differences in actual risk. When

evaluating breast cancer rates, the following questions should be considered:

- What is the source of the rate information?
- What type of rate is being evaluated?
- Does the rate represent a specific year or has it been averaged over several years?
- Has the cancer rate been adjusted for age or other factors?
- What US population standard was used in the age-adjustment?
- Are the rates pre- or post- 1996 (NY State rates only)?
- Could geographic differences be due to differences in risk factors?

The answers to these questions will help guide informed decision-making about the meaning and implications of breast cancer rates. ■

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WEB RESOURCES:

How changes in US Census counts affects NCI cancer rates:
<<http://www.nci.nih.gov/newscenter/pressreleases/Census2000>>

NY State Maps by ZIP Code
<<http://www.health.state.ny.us/nysdoh/cancer/csii/nyscsii.htm>>

Age Adjustment
<<http://www.health.state.ny.us/nysdoh/cancer/nyscr/age.htm>>

NY State Cancer Registry
<<http://www.health.state.ny.us/nysdoh/cancer/nyscr/nyscr.htm>>

Prepared by

Zev Ross, M.S., Consultant, BCERF

*Based on original 1997 version by Banoo Parpia, Ph.D., Senior Research Associate,
Division of Nutritional Sciences and Carmi Orenstein, M.P.H., BCERF Assistant Director and Health Educator.*

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