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Variety is the Spice of Life

Spring is always a time of year when we seem to feel more alive. The earth is awakening from a long winter's sleep (at least in the northern Hemisphere) and we may feel that way too. This issue of the Journal hopes to also bring an awakening to your professional interests. If variety is the spice of life then this issue might be considered 'spicy.' It includes articles that deal with a variety of subjects, all of which I think are of interest to medical registrars. The topics range from seasonal residency of patients, identifying family medical histories, and preparing for an ACOS survey, to how the pathologist and registrar can help educate patients.

"The Effect of Seasonal Residence on Cancer Incidence Rates" by Boscoe and McLauglin addresses a frequent problem for registries located in areas with parttime residents. Although the article is based on New York data, many southern and western states, such as Florida, Texas, Arizona, and California have patients who may live in the area for only part of the year. Patients who have serious diseases may be diagnosed in one state/region while 'resident' in another. This may inflate cancer incident rates in the diagnosing/treating area. Thus, multiple residences may account for some cancer excesses.

Forrester and Merz in "Identification of Family History of Birth Defects by a Birth Defects Registry" discuss a situation that is also of interest to other medical registries, especially cancer. For example, obtaining accurate family histories can allow for possible genetic tracking of disease. This article describes the methodology used by one program to identify family history.

An interesting concept is presented by Strobel in his paper, "A Role for Pathologists and Registrars in the Education of Patients with Prostate Cancer." Instituting a similar education program may help registrars become more visible to other hospital departments.

"ACOS Survey Preparation for a Community Hospital" offers help to cancer registrars facing the specific problem of preparing for regular surveys of their hospitals' cancer programs. In a 'How I Do It' article, Ceselski and colleagues suggest that procedures developed at their hospital may be useful to others in a similar situation.

The occasional column, The Book Shelf, appears again in this issue. Four recent books are reviewed on topics ranging from a feminist view of breast cancer to Dr. Folkman and angiogenesis.

The Special Focus on clinical research which was scheduled for this issue has been postponed.

Amy M. Fremgen, PhD, CTR

Editor

Original Article

The Effect of Seasonal Residence on Cancer Incidence Rates

Francis P. Boscoe, PhD^a, Colleen C. McLaughlin, MPH, CTR^a

Abstract: Analysis of local area cancer data in New York State shows that areas with high seasonal occupancy are more likely to have elevated incidence rates of all types of cancer. This results from an occasional discrepancy between the decennial census and health care providers as to the assignment of place of residence. For those individuals who migrate seasonally, primary residence may be ambiguous, resulting in a potential misclassification of residence in either the numerator or denominator. Since the relationship between seasonal occupancy and cancer incidence varies by region within the state, there is no adjustment that can be uniformly applied. When conducting local cancer investigations, however, attention to the possibility of multiple residences on a case-by-case level can be used to account for some cancer excesses.

Key words: ascertainment, cancer incidence, duplicate cases, seasonal residence

Introduction

The tendency of many older Americans to migrate on a seasonal basis results in artificially high cancer incidence rates in areas with a large proportion of seasonal residents. Such elevated rates may lead to erroneous hypotheses regarding cancer etiology, especially given the recent increased interest in ecologic studies of small geographic areas. 1,2,3 The finding of adverse health outcomes concentrated in resort areas is not new. Statisticians in Victorian England were alarmed by the observation that mortality rates were highest in resort areas such as Brighton and Blackpool. The explanation was that these towns contained a large proportion of elderly, retired persons, and the technique of age-adjustment gained currency as a result. 4 In the case of seasonal migration patterns within the United States, the problem is more subtle. Individuals who maintain two residences are typically counted at their primary residence in the decennial census, but may provide either of their residential addresses to their health care provider when diagnosed with cancer. While this paper focuses on cancer incidence, the same pattern may be found with other incidence data. For example, the state of New Jersey passed a law in 1998 requiring crime statistics to reflect variation in seasonal population, motivated in part by excessive rates in beach communities.5 College campuses, military bases, and migrant farm communities are other areas where the reporting of incidence rates may present difficulties, though the age characteristics of the populations of these areas result in a minimal contribution to the overall cancer

A substantial proportion of Americans maintain a dual residence, particularly in the 55-84 age group, 6 in which

over two thirds of incident cancer cases are diagnosed. Such individuals typically divide their residence by season; the warm months of the year are spent in one location, the cold months in another. These include "snowbirds", who divide their time between Sunbelt and Snowbelt states, such as New York and Florida, as well as those who migrate within a region, such as between Philadelphia and the New Jersey Shore. Such individuals are more likely to be married, wealthy, college educated, and white than the elderly population at large.7 The Census Bureau does not measure dual residence, and most of the attempts to quantify seasonal migrants have relied on survey data. Krout found that roughly one of seven elderly residents of a nonmetropolitan county in western New York State migrated on a seasonal basis, with over three quarters traveling to the Southeast.8 In an Arizona-based survey, McHugh, Hogan and Happel found that 14% of the overall population and 24% of the population over 65 occupied a secondary residence within the past year.9 Hogan and Steinnes reported that 9.2% of elderly Minnesotans migrate seasonally. 10 A recent Census Bureau paper acknowledged that differences in population estimates between the 1996 American Community Survey (ACS) and the 1996 intercensal estimates for a county in south Florida may be attributable to seasonal migrants.11

The elevation in cancer incidence rates in areas with high seasonal occupancy arises from the fact that some people are counted by the census at one address, but are counted in a cancer registry at another address, via information supplied by a reporting institution. Based on the survey results reported above, perhaps one tenth to one fifth of all cancer patients have a choice to make when providing an address

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[&]quot;The Effect of Seasonal Residence on Cancer Incidence Rates" New York State Cancer Registry, New York State Department of Health, Albany, NY.

Address correspondence to: Francis P. Boscoe, PhD, New York State Cancer Registry, New York State Department of Health, 536 Corning Tower ESP, Albany, NY 12237; telephone: (518) 474-2255; FAX: (518) 473-6789; e-mail: fpb01@health.state.ny.us.

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Table 1. Effect of Seasonal Population on Standardized Incidence Ratio, Hypothetical Example

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Incident Cases Observed	Incident Cases Expected	Standardized Incidence Ratio
15	15	1.00
23	15	1.53
	Incident Cases Observed	Incident Cases Observed Expected

to a health care provider. In most instances, the choice they make is an obvious one and corresponds with where the census considers them to live. For example, a person spending three winter months in Arizona and the remaining nine months in Ohio is likely to be counted by both the census and a cancer registry as an Ohio resident. In other situations, however, the choice may be ambiguous, or an alternative choice may be made for reasons of practicality, convenience, or privacy concerns. For instance, an individual who becomes symptomatic at the beginning of a planned six-month stay at his cottage in Upstate New York may provide his local address to the hospital, even though he is counted by the census as a New York City resident.

Only a small number of individuals making such a divergent choice are required to have a substantial impact on local incidence rates. Consider a hypothetical village in the Thousand Islands region of New York State that has a permanent, year-round population of 600 and a summer peak population of 4,600. These estimates may appear severe, but are typical of such areas. 12,13 Assume that of the 600 permanent residents, 15 are diagnosed with cancer over a given period of time, and assume that this corresponds precisely with the number of cases that would be expected measured against some standard population. Of the 4,000 part-time residents, 100 are diagnosed with cancer over the same period, again equal to the number that would be expected. Supposing that 25 of these 100 cases are diagnosed while the patient is living in the village (based on an average stay of 3 months), and one third of these provide their village address, then the standardized incidence ratio for the village is artificially inflated by 53% (Table 1).

While this problem is partially attributable to the Census Bureau rule that places each individual into a single, fixed place of "usual residence", 14 making the enumeration more flexible would not eliminate the problem. For example, New Jersey derives a mean annual population by counting seasonal residents fractionally. Using this approach in our hypothetical example, the population count would be 1,600 people (600 permanent residents plus 4,000 quarter-residents). This may be a useful measure for some purposes, but would have the effect of producing a deficit in cancer rates. In a population of 1,600, 40 cancer diagnoses would be expected, but the registry would record 23 as before, an artificial deficit of 42%.

Methods

Two approaches were taken in order to document the effect of elevated cancer incidence rates in seasonally occupied areas. First, cases were selected from the New York

State Cancer Registry (NYSCR) and matched against property tax records in order to identify cases that are likely to have a seasonal address listed as the address of diagnosis. Second, ecologic linear regression was performed to establish the correlation between the fraction of the housing units that is seasonally occupied and the standardized incidence ratio (SIR) for all sites of cancer. Regression was repeated on a regional basis in four broadly defined resort areas of the state to demonstrate that the strength of the correlation is regionally variable.

Case Matching between Cancer Registry and Property Tax Records

Cases for matching were selected from the New York State Cancer Registry. Cases were selected based on International Classification of Diseases for Oncology, Second Edition codes C00.0 through C80.9, behavior code 3, corresponding to all invasive malignant cancers. The New York State Cancer Registry has been a legally mandated statewide cancer registry since 1973, and currently participates in the National Program of Cancer Registries. NYSCR is currently over 99% complete for the time period studied, based on the North American Association of Central Cancer Registries (NAACCR) incidence to mortality ratio method. 16,17,18 The selection was limited to cases with age of diagnosis between 55 and 84 years of age, an age range in which people are most likely to own a seasonal residence. The selection was limited to case with age of diagnosis between 55 and 84 years of age, an age range in which people are most likely to own a seasonal residence.

Two hundred ten cases were selected with a diagnosis year of 1994 or 1995, half with diagnosis ZIP codes corresponding to resort towns within the Thousand Islands region of New York State, and half with diagnosis ZIP codes from a nearby non-resort town. For the period 1993 to 1997, the resort towns selected had a SIR of $\hat{1}.55$ and the non-resort town an SIR of 1.03 for all cancers diagnosed between the ages of 55 and 84, using New York State as the standard. According to 1990 census data, 48% of the residential properties in the resort towns were occupied seasonally, compared with 5% in the non-resort town. The selected cases were matched against property tax records supplied by the New York State Office of Real Property Services (ORPS) for the year 1995. When a matching record was found in the property tax records, the physical address of the property was compared with the tax billing address. A difference in these two addresses means that the owner arranged for his or her tax bills to be sent elsewhere, an indicator of a seasonal residence and thus a potentially misclassified primary address.

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Physical address matches tax-billing address	50%	92%	
Tax-billing address is elsewhere in NY State	39%	6%	
Tax-billing address is outside of NY State	11%	2%	

Table 2 provides evidence in support of the use of property tax records as an indicator of seasonal residence. The table suggests that 50% of the residences in the resort towns and 8% of the residences in the non-resort town are

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Linear Regression

Cases selected for the linear regression included all invasive malignant cancers in the NYSCR diagnosed between 1993 and 1997 with an age of diagnosis between 55 and 84 (n=302,093). The inclusion of all sites of cancer minimizes the impact of geographic variation in site-specific etiologies and maximizes the chances of identifying an effect due to seasonal residence. The percentage of homes seasonally occupied was obtained by taking the ratio of seasonal and recreational housing units to the total number of housing units tabulated in the 1990 census. Both the cases and percentage of homes seasonally occupied were aggregated by ZIP code. ZIP code is the finest level of geography for which the cancer registry is complete, with only 33 of the 302,093 cases missing this information.

The ZIP code boundaries determined as part of the 1990 census represented coarse approximations in many areas, particularly rural areas. As a result, we used 1998 ZIP code boundaries provided by Geographic Data Technology (GDT), with the 1990 housing data retabulated to conform to the 1998 boundaries. To limit the effect of unstable rates, we grouped ZIP codes together until there were at least 20 cases in each geographic unit. Neighboring ZIP codes were grouped according to similar levels of seasonal home occupancy. The eight New York State ZIP codes that were either created or experienced boundary changes between 1990 and 1998 according to the Postal Bulletin were also grouped.¹⁹ The result was a total of 1,351 geographic units, reduced from an original total of 1,593 ZIP codes. For the sake of simplicity, the term ZIP code will be used for the remainder of the paper to refer to these 1,351 units. SIRs were calculated for each ZIP code using the statewide rate as the standard. Age adjustment was based on three age strata: 55 to 64, 65 to 74, and 75 to 84.

Linear regression was performed with SIRs as the independent variable and the percentage of homes seasonally occupied as the dependent variable. Since a majority of ZIP codes have little or no seasonally occupied housing, including these in the model potentially masked the relationship of interest. As a result, the cutoff point that maximized the correlation was first determined.

Regional analyses were also conducted for four broad resort regions defined at the county level that encompass most of the locations with high seasonal residence: Adirondacks, Thousand Islands, Catskills, and Long Island (Figure 1). The four areas encompass 27% of the ZIP code areas of the state, 47% of those where at least 5% of the homes are seasonally occupied, and 87% of those where at least 40% of the homes are seasonally occupied. A separate linear regression was performed on the data from each of these four regions to assess regional variation in the strength of the relationship between seasonal residence and cancer incidence.

One hypothesis is that regional variation may be attributable in part to the distance between dual residences. That is, when a person receives a positive screening result or becomes symptomatic while at their seasonal residence, their choice of a health care provider, and the address they supply to this provider, may be influenced by their distance from their primary residence. We assumed that the locations of primary residences follow the distribution of population

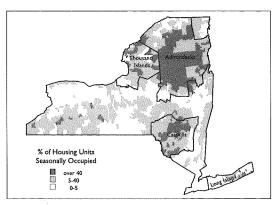


Figure 1. New York State seasonal residence and broadly defined resort regions

generally, and calculated the distance from each ZIP code to the nearest metropolitan center. This distance was used as a second dependent variable in the linear regression.

Results

Case Matching between Cancer Registry and Property Tax Records

A comparison of property address with tax-billing address for all residential properties in the study area yielded the results shown in Table 2. The table suggests that 50% of the homes in the resort towns are occupied seasonally, which compares favorably with the 1990 census estimate of 48% for all noncondominium housing units in these towns. For the non-resort town, the number of seasonal homes is estimated at 8%, compared with a 1990 census estimate of 5%.

We were able to match 82 (78%) of the cancer cases from the resort towns to the tax records. Of these matches, 11 had a billing address that was different than the property address. Four of these billing addresses were in the Rochester area, which is the nearest metropolitan center to the Thousand Islands, and 3 were out-of-state. The remainder were in other areas of New York State. Using telephone directories and other sources, we were able to confirm the second address for each of these 11 cases. The 23 unmatched cases in the sample (22%) represent those who do not own property within the study area, and may include some additional seasonal residents (such as a winter resident of Rochester who summers at his nephew's home in the Thousand Islands), but any such seasonal residents could not be identified through this analysis. Extrapolating these results to all of the resort towns (that is, assuming that 11 out of every 105 cases would be found to have a primary address elsewhere), reduces the overall SIR for these towns from 1.55 to about 1.39. For cases from the non-resort town, we were able to match 88 (84%) of the cases to the tax records. Of these, each one had a billing address that matched the property address, suggesting that all were year-round residents. The overall SIR for this town of 1.03 would be unaffected.

Ecologic Regression

The linear regression of percent of homes seasonally occupied against SIR reveals a strong and positive correlation (Figure 2). This correlation is maximized when the sample is restricted to ZIP codes with at least 5% of homes seasonally occupied ($r^2=0.25$, p<0.0001). If the predicted

SIRs from the linear regression model are used to revise the expected number of cases in each ZIP code, then the total number of ZIP codes in the state with an excess greater than 50% is reduced from 47 to 16. Such a global correction is not appropriate, however, because the residuals are spatially autocorrelated; that is, the relationship varies in strength depending on location within the state. Figure 3 highlights the residuals for the Thousand Islands and Long Island areas, showing that relationship between SIR and seasonal residence is much stronger in the former. As a result, the model tends to underpredict SIR values in the Thousand Islands, while overpredicting those on Long Island. The calculation of separate regression lines for each region further illustrates this point (Figure 4). The slope of each line is positive, but the relationship in the Thousand Islands is significant (r^2 =0.46, p<0.0001) while that in Long Island is not (r²=0.08, p=0.11). The Adirondacks and Catskills are both significant at p=0.05.

Since the northern part of the state has the strongest correlation and is the furthest removed from any metropolitan center, the hypothesis that the reporting of seasonal addresses to medical providers is related to distance seems reasonable. However, adding distance to the model resulted in only marginal improvement in explanatory power, with an r² value of 0.27.

Conclusions

We have presented several kinds of evidence suggesting the systematic elevation of cancer incidence rates in areas with seasonally resident populations. The elevation results when individuals provide addresses to health care providers that fail to match the address tallied by the Census Bureau. In New York State as a whole, 25% of the cancer rate variation in such areas can be explained in this manner, and in the northern counties of the state the figure exceeds 40%. The strong regional variation precludes the ability to make any global correction to cancer incidence rates. Indeed, the decision to provide a seasonal address to a health care provider is a complex and sometimes ambiguous one and may be influenced by voter registration status, tax issues or privacy concerns, all of which may vary regionally and within a region. Further study would be needed to address these kinds of motivational issues. Incorporating distance between primary and seasonal residence into the model did not provide much additional explanatory power.

There is no simple solution to the seasonal residence problem. While we were able to identify a number of specific cases where the address on the registry did not match the apparent primary residence, the evidence was insufficient to justify modifying the address fields for these cases in the registry. The Commission on Cancer's Registry Operations and Data Standards (ROADS) states that for persons with more than one residence, "use the address the patient specifies if a usual residence is not apparent".20 An awareness of this issue by reporting facilities and central registry staff, on the other hand, could result in improved data collection. Address information is usually abstracted from the face sheet, but additional address information may be obtainable from accounting and billing departments. Registrars in areas with high seasonal occupancy might consider using this additional address information in determining the primary residence. In addition, the social history section of the patient's history and physical may state whether or

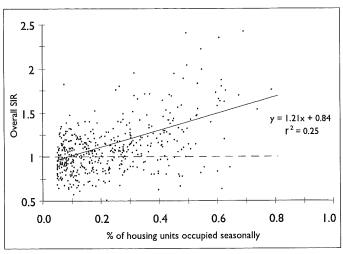


Figure 2. Seasonal residence versus SIR, New York State

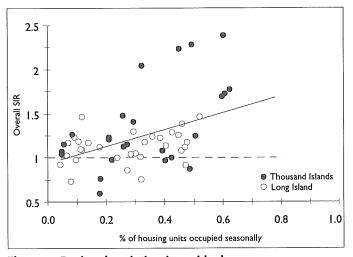


Figure 3. Regional variation in residuals

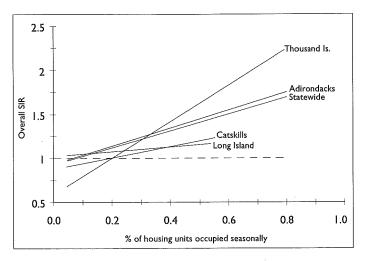


Figure 4. Seasonal residence versus SIR, resort regions within New York State

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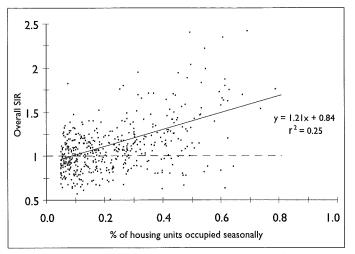


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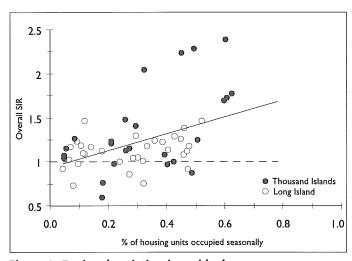


Figure 3. Regional variation in residuals

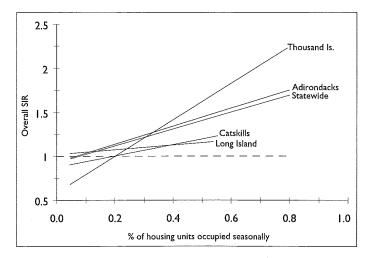


Figure 4. Seasonal residence versus SIR, resort regions within New York State

not the patient is a seasonal resident. This information could be entered in the "Text-Remarks" field, even if the patient's primary residence cannot be obtained, and would facilitate the eventual determination of primary residence.

Central registry staff can assist by identifying the facilities most likely to be affected by this issue and raising the topic with them. A NAACCR Geographic Information Systems (GIS) Workgroup has recently been convened to consider geocoding issues such as those raised here, and recommendations will be forthcoming.²¹

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We do recommend that seasonal residence be considered as a possible source of bias whenever a local cancer investigation is conducted. Through the use of specialized databases that may be accessible by central registry staff, such as motor vehicle records, vital records, and tax records, along with public domain information such as telephone directories and the Social Security Death Index, it may be possible to identify alternative places of residence and thus account for some or all of the cancer excess in a particular area. The process is labor intensive, but far less so than a full-fledged case control study.

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