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Rapid reporting of cancer incidence in a population-based study of breast cancer: One constructive use of a central cancer registry

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Summary

To support a study of genetic risk factors for breast cancer, the North Carolina Central Cancer Registry has implemented a rapid reporting procedure for hospitals in the study area. This system permits the identification of newly diagnosed breast cancer cases within a very short time period (less than one month). The procedures are straightforward, cost-effective, and greatly benefit the objectives of tissue collection and interviews with the cases. This article describes the rapid reporting procedures and their potential impact for population-based research. For the objective of making generalizable risk statements, the necessity of population-based research is stressed; participation with central cancer registries is endorsed for this and other molecular epidemiologic applications.

Introduction

The Carolina Breast Cancer Study (CBCS) is a population-based case-control study operating in 24 counties of predominantly rural central and eastern North Carolina (Figure 1). The CBCS is administered by the Lineberger Comprehensive Cancer Center of the University of North Carolina School of Medicine. This study aims to conduct interviews with breast cancer cases and to collect blood as a source for germ line DNA. Consequently, there is a need to contact the cases as soon as possible after diagnosis, before patients have succumbed to their breast cancer and before systemic treatment has begun which may substantially lower the lymphocyte levels and make blood drawing troublesome. The CBCS sought a close collaboration with the North Carolina Central Cancer Registry (CCR) as it designed this project. For the purposes of complete case-finding, a system was developed for identifying breast cancer cases as rapidly as was feasible after their diagnosis. To encourage cooperation, the aegis of the state law implementing cancer registration in North Carolina was used as an operational tie between the CBCS and the CCR [1]. This no doubt benefitted hospitals' willingness to report their data. Also, a nominal payment provided added incentive. Overall, this rapid reporting system is quite successful; it is similar to a method that has

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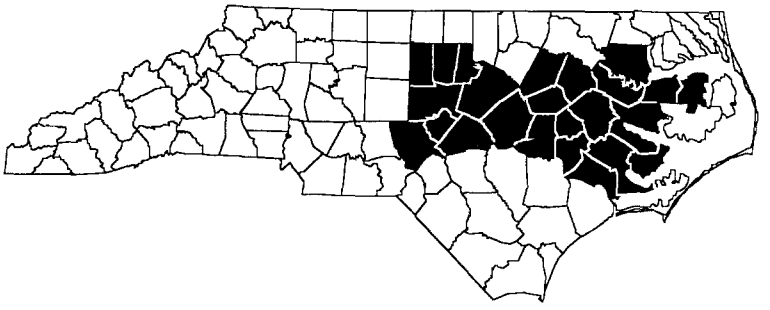

Figure 1. The study area of the Carolina Breast Cancer Project (shaded)

been used for years by the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) registries for nested case-control studies.

Methods

The CBCS uses a specialized database nested within a central cancer registry system, patterned after a design from Laszlo, et al. [2]. This nested database mechanism is implemented only for the duration of a given research project and involves reporting only specific cancer(s) that are under investigation; e.g., breast cancer in the case of the CBCS. Employing such a focused, rapid reporting process optimizes limited resources for case ascertainment in support of epidemiologic research [3].

The rapid case ascertainment approach is an efficient modification of the usual reporting methods. Hospital registrars routinely do case-finding using pathology reports, checking them daily or a few times each week. Upon the identification of a cancer diagnosis, the case record is "flagged" for eventual abstracting when the medical record documentation is completed for all clinical evaluation studies and after the first course of treatment is fully initiated. This delay until chart completion or implementation of the first course of care is often two or three months. The American College of Surgeons conventionally permits up to four months lag for performing timely abstracting in its Approved Cancer Programs. By using a rapid reporting plan, cases are identified and the Central Cancer Registry is notified immediately after the pathology report review.

A schematic representation of the steps for rapid reporting is presented in Figure 2. First, cases are identified through pathology reports. These are reviewed regularly, weekly or more often. The records of private pathology services are received since some of the smaller hospitals do not have in-house pathologic review. Likewise, discharge lists are inspected for cancer-related diagnostic codes. Next, documentation of the newly ascertained case is sent to the CCR. Most facilities send a facsimile of the pathology report for the rapidly ascertained cases, with the requested supplemental information hand-written on the report. Other hospitals compile a separate listing, with some registries choosing to send copies of their case abstract. For a few of the smallest hospitals, monthly visits are made by CCR staff to review and obtain relevant pathology reports and patient information. These various documents contain the brief study-specific details that must be collected. These data include: patient name, age, race, address, phone number, county of residence, diagnosing physician, and pathologic diagnosis. When these data are received by the CCR/CBCS field representative, they are collated for transmittal to the CBCS operation office. The eligibility of these cases for

the CBCS study is determined and sampling is done prior to the arrangements for interviews.

Discussion

In North Carolina, the Carolina Breast Cancer Study has employed the rapid reporting system successfully. In the 24-county study area, over 1600 new breast cancer cases were rapidly identified in the first year of study; some cases were transmitted to the CCR within two days of their initial biopsy, and virtually all were reported within the two week to one month goal.

Some of the hospitals were initially reluctant to take part in the CBCS. However, the CCR has close contact with many local groups including community organizations and units of the American Cancer Society [4,5]. Presentations were made before the medical staffs of each hospital to preview the CBCS objectives and explain the rapid reporting process. These "face-to-face" sessions did much to ease tensions and get the system started. Some of the local medical oncologists were concerned over losing their patients to the large treatment centers. Extensive efforts were made to assure physicians that patient care is not an objective of epidemiologic studies and to acknowledge the appropriateness of keeping patients in their local community. The CBCS was reviewed and approved by the Institutional Review Board for Research Involving Human Subjects (IRB) or its equivalent at each of the 26 hospitals in the 24-county study area prior to implementation of the rapid case ascertainment. Some specialized research procedures associated with the CBCS, e.g. obtaining tissue blocks and taking blood samples, leads to other nuances when done in the context of cancer registration.

All of the hospital registries in the CBCS study area have been compliant with the rapid reporting technique. In fact the staffs of all 36 hospital registries in North Carolina have received training in the rapid reporting methods. Among those hospitals in the study area without a registry, staff in the medical records and pathology

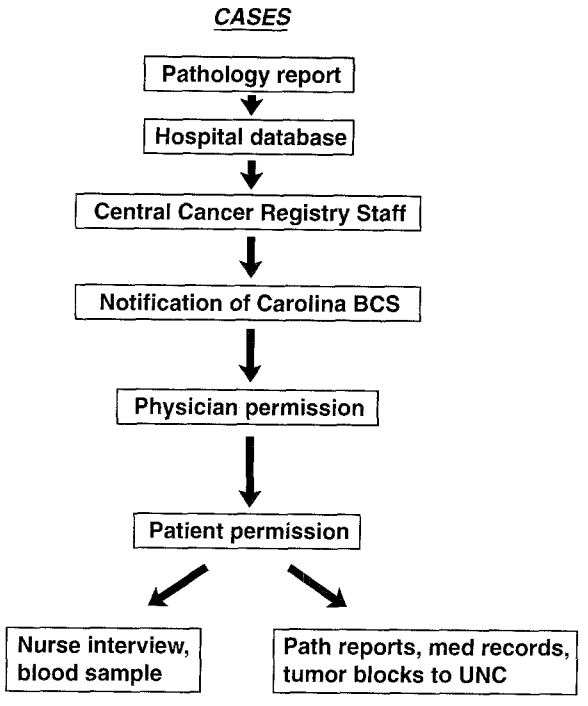

Figure 2. Diagram of rapid reporting system

departments cooperate with the rapid reporting system. The CBCS provides payments for rapid reporting in order to help make hospital registries into revenue-generating services, thereby enhancing the continued support by hospital administrators [6].

Physicians have had mixed responses to the CBCS. Some are more supportive of outreach activities from large treatment centers than others. However, none has opposed the rapid reporting concept or resisted its implementation.

Conclusions

Linking central cancer registries with epidemiologic research efforts should be actively fostered across the United States [7,8]. The system described here provides an efficient means of ascertaining cancer cases rapidly. The cooperation with and enthusiasm for the method by tumor registrars and medical records staff is quite heartening as rapid reporting evokes a productive

connection between community hospitals, hospital-based cancer registries, and the state central cancer registry [3]. The experience presented here may be helpful to central cancer registries and other epidemiologic researchers.

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References

1. Aldrich TE, Atkinson DA, Hines A, Smith CG: The establishment of a population-based cancer registry for North Carolina. NC Med J 51:107-112, 1990
2. Laszlo J, Cox E, Angle C: Special article on tumor registries: The hospital tumor registry — present status and future prospects. Cancer 38:395-402, 1976
3. Aldrich T: Research use of central registries. *In:* Menck H, Smart C (eds) Central Cancer Registries — Design, Management, and Uses. Harwood, Switzerland, 1994, pp 259-290
4. Graber D, Aldrich T: The citizen participation model: Working with community action groups in assessing environmental and health hazards. Carolina Health Serv Rev [Summer]:20-33, 1993
5. Graber D, Aldrich TE: Working with community organizations to evaluate potential disease clusters. Soc Sci Med 37:1079-1085, 1993
6. Southerland HF: How to become a revenue-producing department. The Connection [April]:1-2, 1994
7. Tucker TC, Friedell GH: Using cancer registry data in primary care practice. Primary Care and Cancer 14(3): 33-36, 1994
8. CDC (Centers for Disease Control): State cancer registries: status of authorizing legislation and enabling regulations — United States, October 1993. Morbidity and Mortality Weekly Report 43(4):71-75, 1994