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Indexing

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For your convenience, the *Journal of Registry Management* is indexed in the 4th issue of each year and on the Web (under "Resources" at http://www.ncra-usa.org/jrm). The 4th issue indexes all articles for that particular year. The Web index is a cumulative index of all *JRM* articles ever published.

Letter from the Editor

Dear Colleagues,

A change in seasons has also brought a change in the Commission on Cancer (CoC) Standards. The CoC released the new standards and hosted its first educational meeting in November. These new standards have been incorporated into 9 chapters. For more information on the 2020 Standards or upcoming CoC education, visit **https://www.facs.org/quality-programs/cancer/coc/2020-standards**.

This issue of the *Journal of Registry Management* contains 2 original manuscripts. We start with Leah L. Zullig, PhD, MPH, and colleagues discussing the vast array of data sources available from the Veterans Health Administration (VHA). In the second manuscript, Ugochukwu Okoroafor and associates discuss the limitations of paper medical records in low- and middle-income countries. In the *How I Do It* section, Wilson Apollo, MS, RTT, CTR, explains the basic principles of radiation therapies for cancer registrars. Also included in this edition is a poster from NCRA covering the challenges of survivorship care plans.

The Journal of Registry Management awards a "Best Paper" for 1 original manuscript each year. We are reviewing past winners in the section titled, "A Look Back: Best Papers from the 2010s." The 2013 winner reviews the impact of benign brain tumors. The 2014 winner discuss surveillance data on stillbirths.

The last 2 pages of the JRM contain the Call for Papers and Information for Authors. Submissions of manuscripts or articles are accepted at any time. The "How I Do It" section comes from readers who want to share their expertise and ideas on varying topics.

Special Call for Articles

The Commission on Cancer (CoC) has released the *Optimal Resources for Cancer Care: 2020 Standards.* Cancer registries are looking for guidance on implementing these new standards, and we are seeking articles on this topic. Please share your expertise with your cancer registrar colleagues.

Regards,
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Original Article

Summary of Veterans Health Administration Cancer Data Sources

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Abstract: Objectives: The Veterans Health Administration (VHA) is a leader in generating transformational research across the cancer care continuum. Given the extensive body of cancer-related literature utilizing VHA data, our objectives are to: (1) describe the VHA data sources available for conducting cancer-related research, and (2) discuss examples of published cancer research using each data source. Methods: We identified commonly used data sources within the VHA and reviewed previously published cancer-related research that utilized these data sources. In addition, we reviewed VHA clinical and health services research web pages and consulted with a multidisciplinary group of cancer researchers that included hematologist/oncologists, health services researchers, and epidemiologists. Results: Commonly used VHA cancer data sources include the Veterans Affairs (VA) Cancer Registry System, the VA Central Cancer Registry (VACCR), the Corporate Data Warehouse (CDW)-Oncology Raw Domain (subset of data within the CDW), and the VA Cancer Care Cube (Cube). While no reference standard exists for cancer case ascertainment, the VACCR provides a systematic approach to ensure the complete capture of clinical history, cancer diagnosis, and treatment. Like many population-based cancer registries, a significant time lag exists due to constrained resources, which may make it best suited for historical epidemiologic studies. The CDW-Oncology Raw Domain and the Cube contain national information on incident cancers which may be useful for case ascertainment and prospective recruitment; however, additional resources may be needed for data cleaning. Conclusions: The VHA has a wealth of data sources available for cancer-related research. It is imperative that researchers recognize the advantages and disadvantages of each data source to ensure their research questions are addressed appropriately.

Key words: data sources, neoplasms, oncology, population health, research methods, Veterans Health Administration

Introduction

The Veterans Health Administration (VHA) is the largest integrated provider of cancer care in the United States, diagnosing and/or treating approximately 50,000 patients at 129 medical centers annually.[1,2] In addition to being a leading health care provider, the VHA has also generated transformational research across the cancer care continuum. Pivotal cancer research includes, but is not limited to, linking cigarette smoking to precancerous lesions,[3] demonstrating the superiority of colonoscopy over sigmoidoscopy for colorectal cancer screening,[3] determining that observation is as effective as surgery for the treatment of early-stage prostate cancer,[4] establishing dental treatment guidelines for patients with head and neck cancers,[5,6] and implementing a population-based lung cancer screening program.[7-11] The quality of VHA cancer care has also been thoroughly evaluated[12-15] and the care delivered in the VHA compares favorably with other health insurers and health care systems. For instance, when compared with Medicare, cancer-related imaging is used more efficiently at the VHA[16] and survival rates are higher among older patients with colorectal and non-small lung cancer treated at the VHA.[17] The extensive body of published cancer research is largely possible due to the availability of vast cancer data sources within the VHA. Our objective is to describe existing VHA data sources available for conducting cancer-focused health services research.

VHA Cancer Data Sources

The VHA has several cancer-related data sources, some originating from clinically collected data that are updated daily in the national electronic health record (EHR) system, and others assembled for a specific, often time-limited purpose (eg, a single research study). We describe the primary data sources available within the VHA for conducting cancer-related research (Table 1), the relative advantages of each data source (Table 2), and examples of published work and current research using each data source (Tables 1 and 3).

It is worth noting that the data sources reviewed are those that that are most commonly used or are routinely accessed for clinical operations, health services research, and preliminary, feasibility, retrospective, and observational research studies. Herein, we describe the following 4 related VHA cancer data sources: (1) the Veterans Affairs (VA) Cancer Registry System, (2) the VA Central Cancer Registry (VACCR), (3) the Corporate Data Warehouse (CDW)-Oncology Raw Domain, and (4) the VA Cancer Care Cube (Cube) (Figure 1).

VA Cancer Registry System

In 1998, a VA policy directive established the VA Cancer Registry System which consists of site-based cancer registries that populate the central component of the system, the aggregated VACCR. The VA Cancer Registry System adheres to the standards developed by the North American Association of Central Cancer Registries (NAACCR).[18] The system includes data elements required by the Commission on Cancer's Facility Oncology Registry Data Standards (FORDS) manual (eg, patient demographics, cancer or tumor characteristics, stage of disease)[19] or the Standards for Oncology Registry Entry manual (STORE, which replaced FORDS 2018).[20] Both manuals ensure that registry data are structured and maintained with standardized quality

Table 1. Description of VHA Cancer Data Sources							
VHA Data Source	**Primary Purpose**	**Brief Description**	**Cancers**	**Domains**	**Selected References**	**Data Steward**	**Special Considerations***
VA Central Cancer Registry	- Operations - Clinical - Research	Record of reportable cancers diagnosed or treated in the VHA; data is abstracted and validated by site-based tumor registrars	All cancers	- Identifiers - Demographics - Diagnosis information - First-line of treatment	- Descriptions of VHA cancer incidence[1,2,36] - Treatment patterns[66] - Survival analysis[33,34] - Quality measurement[67] - Exposure studies[68]	- PCS	The timeline for DUA approval may be significant and, once a DUA is in place, receiving data hinges on availability of staff. This may mean that approved DUAs are not processed.
CDW-Oncology Raw Domain	- Operations - Clinical - Research	Information pertaining to cancer diagnosis and care delivery originating from the electronic health record	All cancers	- Identifiers - Demographics - Diagnosis - Treatment	- Cohort identification[49,50] - Case-control studies[50] - Diagnostic evaluations[51]	- NDS	The data have not been cleaned. It is relatively straightforward to link with other CDW data including information about VHA health service use and survival.
VA Cancer Care Cube	- Operations - Clinical - Research	The Oncology Domain files from the CDW are accessible via the Cube	All cancers	- Identifiers (under certain circumstances) - Diagnosis - Treatment	- Cohort identification[52] - Staging and survival[53] - Treatment and survival[54]	- VSSC	The Cube is accessible using the Pyramid platform.
Facility** Oncology Survey	- Operations	Cross-sectional survey of resources available at VHA facilities providing cancer care	N/A	VHA facility: - Staffing - Space - Services - Equipment	- Studies evaluating or controlling for facility characteristics[59,61]	- PCS - HAIG	Site-specific data not available for 2005 survey responses.

Abbreviations: CDW, Corporate Data Warehouse; DUA, data use agreement; HAIG, Healthcare Analysis & Information Group; NDS, National Data Systems; PCS, Patient Care Services; VA, Veterans Affairs; VHA; Veterans Health Administration; VSSC, Veterans Health Administration Support Service Center Capital Assets

* Special considerations are all opinions of the authors based on their personal experiences.

** The Facility Oncology Survey was administered in 2005, 2009, and 2016.

Table 2. Relative Advantages of VHA Cancer Data Sources

VHA Data Source*	Advantage	Disadvantage	Suggested Possible Uses
VA Central Cancer Registry	- Robust quality assurance - Relatively clean and complete data - Ability to link to EHR and administrative data	- Data collection and aggregation not as timely as automated sources - Data acquisition process can be time-consuming and cumbersome - Data does not include information on cancer screening	- Retrospective studies - Case identification of older diagnoses - Comparative outcomes
CDW-Oncology Raw Domain	- Updated every two weeks - Ease of linkage to data tables within the CDW	- May not be clean; prone to including suspected cancers - May require additional time and resources for error-checking and correction of duplicated cases	- Retrospective studies - Case ascertainment of recent diagnoses
VA Cancer Care Cube	- Access to up-to-date data (data updated every two weeks) - Possible to extract information "on your own" - Ability to create "own" reports and cross-tabulations	- May not be clean; prone to including suspected cancers - May require additional time and resources for error-checking - May require chart reviews to confirm clinical information (eg, date of diagnosis)	- Descriptive information and preparation for research - General case counts (these case counts may be overestimated) - Case ascertainment of recent diagnoses

CDW, Corporate Data Warehouse; EHR, electronic health record; VA, Veterans Affairs; VHA, Veterans Health Administration.

* Data sources described are those where data is available at the case level.

Table 3. Recent Health Services Research and Development Studies using VHA Cancer Data Sources

Grant Number and Title	Cancer Type	VHA Data Source	Data Elements
CDA 13-025 Colorectal Cancer Survivorship Care in the Veterans Affairs Healthcare System	Colorectal cancer	- VA Central Cancer Registry - Corporate Data Warehouse - VA Cancer Care Cube	- Clinical information - Demographic information - Health service utilization
CDA 16-151 Implementing Shared Decision-Making for Cancer Screening in Primary Care	Lung cancer	Corporate Data Warehouse (health factor data and patient tables)	- Clinical information - Demographic information - Outpatient utilization - Clinical reminders - Cancer risk factors - Patient-reported cancer screening/ outcomes
IIR 12-378 Impact of Family History and Decision Support on High-Risk Cancer Screening	Colorectal cancer	Corporate Data Warehouse	- Clinical information - Demographic information - Provider information
IIR 16-232 Directed Evaluation of Provider Learning Modules to Prevent Venous Thromboembolism after Major Cancer Surgery	Multiple	- Surgical Quality Improvement Program - Veterans Information Systems and Technology Architecture - Computerized Record System - VA Cancer Care Cube	- CPT codes - Number of cancer cases

CDA, Career Development Award; CPT, current procedural terminology; IIR, investigator-initiated research; VA, Veterans Affairs; VHA, Veterans Health Administration.

Figure 1. Data Flow Between VHA Cancer Data Sources
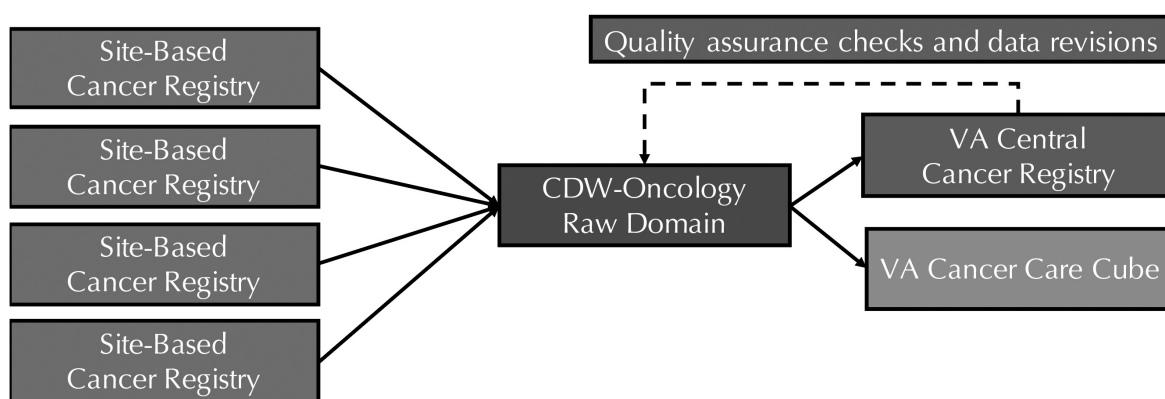
CDW, Corporate Data Warehouse; VA, Veterans Affairs; VHA, Veterans Health Administration.

controls and thus support the meaningful evaluation of cancer diagnoses and treatment. The VA Cancer Registry System also includes cases captured by medical centers whose geographic regions are covered by the National Cancer Institute (NCI)'s Surveillance, Epidemiology, and End Results (SEER) Program.[21] Lastly, the VA Cancer Registry System incorporates additional VHA-defined data elements (eg, era and branch of military service, exposure to asbestos, Agent Orange, and ionizing radiation).

It is worth noting that the VHA is distinct from other military health care providers (eg, Department of Defense) and does not routinely share cancer registry data with external providers. In an effort to provide a complete understanding of the national burden of cancer, VHA Directive 1072 enables VHA medical centers to report cancer data to state registries that completed a data-sharing agreement and have satisfied VHA data security standards.[22] The Edward Hines Jr. VA Hospital (Chicago, Illinois), Michael E. DeBakey VA Medical Center (Houston, Texas), George E. Wahlen VA Medical Center (Salt Lake City, Utah), and Kansas City VA Medical Center (Kansas City, Missouri) are examples of VHA facilities that successfully report cancer data with their affiliated state cancer registry.

Site-Based Cancer Registries: Since 2001, all VHA medical centers diagnosing or treating patients with cancer have implemented an operational cancer registry.[2] Each site-based registry is maintained by at least 1 registrar (typically a National Cancer Registrars Association [NCRA]-certified tumor registrar), who uses a custom VHA software program called OncoTraX to perform casefinding and follow-up; case abstraction and updating; and data transmission and reporting. Generally, site-based registrars are instructed to abstract cases diagnosed or treated within the VHA, which may necessitate identifying and recording information regarding diagnostic and therapeutic care received outside of the VHA (eg, review of available outside medical records using VistA Imaging Display, a system that integrates clinical images and scanned documents into the EHR).[23] It should be noted that site-based cancer registries do not capture information regarding cancer screening. Consistent with other population-based registries, a registry record is only created for patients that receive a cancer diagnosis including in situ cancers; no registry entry will be created for patients who have undergone screening but do not have a confirmed diagnosis of neoplasia. Exceptions include data on squamous and basal cell carcinomas with positive lymph nodes or distant metastasis at diagnosis, intraepithelial neoplasia grade III (eg, high-grade dysplasia bordering on in situ), and monoclonal gammopathy of undetermined significance. Cases of nonmalignant primary intracranial and central nervous system tumors are required to be abstracted and reported nationally.[24]

Site-based cancer registry data have been used to estimate the incidence of multiple primary malignancies[25] and compare patterns of diagnosis, treatment, and survival in non-small cell lung cancer to those reported in the SEER registry.[26] However, the availability and process for acquiring site-based registry data varies and is managed at the medical center-level.

VA Central Cancer Registry: Formally recognized in 2003,[2] VACCR consists of aggregate case abstracts from site-based cancer registries across the VHA. Once cases are abstracted and have completed the site-based quality assurance process, data are transmitted via OncoTraX to the VACCR production database. Using the Rocky Mountain Cancer Data Systems, a Windows-based software program designed to facilitate data entry and statistical analysis, VACCR staff perform additional quality assurance checks (eg, correct duplicated data).[27]

Data aggregation and error-checking processes are a key strength of the VACCR that ensure data are complete, up to date, and meet national standards for cancer reporting. Previous research has suggested that the data available in the VACCR have higher specificity, sensitivity, and positive predictive value (≥90%) compared to cancer case identification using administrative diagnosis codes.[28] Prior studies have demonstrated that patient demographics and cancer-specific data (eg, stage, site, treatment) in the VACCR are ≥90% in both completion and concordance with the EHR.[12,29,30] However, to our knowledge, the contents of VACCR have not been validated through a secondary abstraction or retrospective data comparison. At the time of this manuscript, it is unclear if this data source will continue to undergo quality assurance and oversight processes due to

staffing availability. Therefore, researchers should conduct chart reviews and error-checking to ensure the accuracy and completeness of the data.

Similar to other population-based cancer registries, the VACCR relies on manual abstraction of cancer-specific data from EHRs and supporting documentation, often resulting in significant delays in data entry and aggregation. Delays, which vary across medical centers, are not easily identifiable, and occur for a number of reasons (eg, limited resources or staff). Such delays have contributed to a VACCR reporting delay of 48–72 months. Reporting delays are common in cancer registries; the population-based SEER Program registry has reporting delays of approximately 22 months and the Center for Disease Control and Prevention's National Program of Cancer Registries (NPCR) has a reporting interval of 23 months.[31,32] It is important to note that there are 2 types of reporting delays: (1) the time between receipt of a cancer diagnosis and the case being reported to a registry; and (2) the time until which reported data becomes available to users. Due to these delays, we recommend using the VACCR in instances when capturing recently diagnosed cases is not necessary.

Traditionally, the VACCR has been the most commonly used data source for VHA cancer-related research. The aggregated registry data have been used to evaluate health services and epidemiology research questions related to estimating cancer incidence, survival,[33,34] and describing characteristics of cancer cases,[1,35-37] as well as for case-control studies,[38] and ascertainment of cancer cases for both retrospective studies[39-43] and research involving primary data collection.[44]

Corporate Data Warehouse-Oncology Raw Domain

The CDW[45,46] is a national VHA database comprised of financial, administration, and clinical information which is organized into domains and stored in a Structured Query Language (SQL) relational database structure.[47] The CDW-Oncology Raw Domain is one of many raw domains and consists of a set of relational database tables, of which the following 3 tables are most commonly used for cohort creation: 1 containing general patient information (eg, identifiers); 1 containing diagnosing and/or treating medical center information; and the last containing cancer-specific information (eg, diagnosis, tumor, and treatment characteristics).[45]

The CDW-Oncology Raw Domain and the VACCR originate with information from site-based cancer registries, therefore it is worth comparing these 2 data sources. While a reporting delay still occurs due to limited resources, the CDW-Oncology Raw Domain is updated on a biweekly basis (consistent with most CDW data) and thus is timelier than the VACCR. In addition, being part of the data warehouse allows for relatively easy linkage between CDW-Oncology Raw Domain tables and other CDW data tables (eg, laboratory results, procedures, comorbid diagnoses, vital status, prescription benefits). The most notable limitation is that CDW-Oncology Raw Domain data are "raw," for there are no centralized error identification or quality assurance processes. Therefore, researchers will need to ensure data

validity. One common data cleaning practice is to check for duplicate records and account for individuals with various identifiers across CDW tables. Despite this limitation, the CDW-Oncology Raw Domain has demonstrated similar sensitivity and specificity (≥90%) for colorectal cancer case ascertainment when compared to the VACCR and administrative diagnostic codes.[48]

CDW data and the CDW-Oncology Raw Domain have been widely used in research. Specifically, these data have been used for patient identification,[49,50] case-control studies,[50] and to address health services research questions related to the identification of delays in cancer diagnosis.[51]

VA Cancer Care Cube

The Cube was designed for oncology stakeholders, including VHA clinicians and operations groups that need access to cancer-related data in near real-time. The Cube, which was built and is maintained by the VHA Support Service Center Capital Assets (VSSC) on the Pyramid platform, is comprised of information contained in the CDW-Oncology Raw Domain tables. Information about incident cancer cases (site-based, regional, national) is pulled into the Cube when identified criteria (eg, diagnosis date, primary cancer site, course of therapy) are applied to the CDW-Oncology Raw Domain tables. Since the Cube consists of raw data, researchers are able to monitor the timeliness and completeness of the data. For example, the Cube includes information on patients with incomplete and complete registry abstraction data, which in turn, allows potential cases to be identified earlier and diagnostic or clinical information to be tracked as it becomes available over time.

Accessing the Cube is different than both the VACCR and CDW-Oncology Raw Domain. First, accessing the VACCR and CDW-Oncology Raw Domain require a fully executed data use agreement (DUA) with Patient Care Services and the Corporate Data Warehouse, respectively. Prior to using the Cube, researchers must submit Institutional Review Board (IRB) approval or a DUA request to Patient Care Services. However, other nonresearch uses, including clinical care, may not be subject to approval processes. Researchers outside of the VHA may access the Cube by identifying a VHA-affiliated collaborator and pursuing regulatory approval (eg, IRB approval or exemption). Second, while the CDW-Oncology Raw Domain typically requires a user within the VHA computing network to access the VA Informatics and Computing Infrastructure (VINCI) and query the data via a Microsoft SQL Server Management Studio, the Cube is a business intelligence application (point-and-click interface) that allows a user to access data over the VA intranet.

A primary advantage of the Cube is a user's ability to create reports and cross-tabulations within the tool via a graphical interface without the need to write SQL queries. Despite increased usability, the ability to validate the resulting reports is difficult to achieve. While data precision is improving, it is important to note that the Cube may overestimate cases and should be used as an upper bound to understand volume (especially when planning a

study). Therefore, researchers may need to conduct chart reviews to confirm the accuracy of cancer diagnoses prior to conducting prospective or retrospective studies.

The Cube has commonly been used for cancer case ascertainment. For example, researchers have used the Cube to prospectively identify patients for qualitative interviews.[52] In addition, the Cube has been used to assess the association between staging and survival in patients with colorectal cancer[53] and to evaluate the relationship between the Commission on Cancer accreditation and treatment and survival in patients with metastatic pancreatic cancer.[54]

Other VHA Cancer Data Sources

There are several additional oncology data resources, which are often used for a specific purpose (eg, a single research study) or to address a specific cancer population, that may be of interest to clinicians and researchers. Below, we highlight 3 data sources: (1) the External Peer Review Program (EPRP), (2) the Facility Oncology Survey, and (3) the Epidemiology of Cancer among Veterans (EpiCAN).

The EPRP is an example of unique data source that is used by VHA officials for monitoring facility performance and determining areas for quality improvement.[55] The EPRP data are narrow in scope (eg, focused on a single cancer during a narrow diagnosis time frame) and contain information that is manually extracted from the EHR and chart abstraction. However, researchers using EPRP data may have to conduct additional chart reviews to appropriately define measures. For example, the Adult Comorbidity Evaluation-27 (ACE-27), a comorbidity measure contained in the lung cancer EPRP data,[56] requires chart reviews to appropriately grade conditions as mild, moderate, or severe.[57] EPRP cancer data have been used in studies focused on evaluating racial disparities in care and survival in patients with colorectal cancer,[14,15,58] assessing the use of expectant management among patients with prostate cancer,[59] and examining refusal of or contraindications with recommended therapy and racial differences in receipt of surgery in patients with non-small cell lung cancer.[56,60]

The Facility Oncology Survey is a cross-sectional survey of all VHA facilities that provide cancer care. The survey was administered by the Healthcare Analysis and Information Group (HAIG) 3 times (2005, 2009, 2016), and captures resource availability—services, staffing, equipment, space—for cancer care delivery. For example, the survey has identified which medical centers have tumor boards and various certifications (eg, American College of Surgeons), as well as documented available imaging technologies and consultation services (eg, inpatient and outpatient palliative care consultations).[61] To access the Facility Oncology Survey data, researchers must first receive DUA approval from Patient Care Services and then send a copy of the DUA to the HAIG. The Facility Oncology Survey has been used for research purposes,[59,61] but it has not been as widely used as the previously described data sources. Researchers focused on describing cancer treatment variation across the VHA should consider using the Facility Oncology Survey to account for medical center characteristics.

In contrast to the other VHA cancer-related data sources previously described, EpiCAN is a research study that incorporates the aforementioned data sources.[62] Specifically, EpiCAN identifies cancer cases using the VACCR and the CDW-Oncology Raw Domain, and provides a comprehensive assessment of VHA cancer care by linking information from the CDW, National Death Index, and the Facility Oncology Survey. Due to these data linkages, the objectives of the EpiCAN study are twofold: (1) to broadly evaluate cancer incidence, treatment, survivorship, and outcomes in the VHA; and (2) to identify improvements in and ensure the delivery of high-quality cancer care. A primary goal of EpiCAN is to create a unified data source for others within the VHA community to use to answer research questions. Other cancer-specific research and operations studies have followed suit and linked VA data sources with supplemental cancer registry sources to develop a unified cancer resource.[63]

Conclusion

The VHA is a nationwide high-volume provider of cancer care and has a wealth of data sources that are well-suited for answering health services, clinical, epidemiologic, and population health research questions. We described several commonly used VHA cancer-related data sources available for prospective and retrospective studies; however, this is not an exhaustive list. Existing data sources are routinely updated, new sources are being created, and non-cancer-specific data sources may also be relevant. For example, additional information available within the CDW (eg, diagnostic codes) have been used successfully to identify cohorts in VHA cancer-related research,[64,65] and thus may be an appropriate approach for addressing many cancer-related research questions. Prior to commencing a study, researchers should understand the advantages and disadvantages of the available VHA cancer data sources to ensure appropriate alignment with their research question and scope.

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Evaluating a Newly Developed System for Electronic Medical Records in Tanzania: An Example of the Experience in Low-Income Countries

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Abstract: The introduction of electronic medical records (EMRs) in health systems in high-income countries has streamlined access to care and quality of patient information. However, in low-income countries such as Tanzania, EMR remains in its initial stages. The aim of this study was to compare completeness of patient information in the paper medical records (PMRs) with that of the newly implemented EMRs. Using hospital records of newly diagnosed breast cancer patients treated at the Ocean Road Cancer Institute, demographic, diagnostic, and treatment data of 328 patients between January 2017 and April 2018 were abstracted and compared between PMRs and EMRs. The results showed that demographic information variables were documented significantly more in EMRs (occupation, 98.5%) compared to PMRs (occupation, 43.3%) ($P < .001$). However, diagnostic and treatment information variables were much less likely to be reported in EMRs (full blood panel, 8.2%) than PMRs (full blood panel:=, 93%) ($P < .001$.) The results showed that EMR utilization corresponded with a marked decrease in the overall documentation rate of patient information compared to the standard PMRs. Multiple barriers affected EMR use. A major one was the lack of EMR connectivity across health systems in the country. Future studies should focus on uncovering the barriers and facilitators to EMR utilization, health care workers perception of available EMR systems, and better ways to improve lifetime sustainability of EMR systems in Tanzania and similar low-income countries.

Key words: Africa, audit, breast cancer, electronic medical records, Tanzania

Introduction

Access to valid, reliable, and complete patient information is fundamental for proper patient management, institutional decision-making, and research. Using medical records, providers are able to make decisions, communicate with patients and other health care providers, and satisfy legal and ethical obligations.[1] Paper medical records (PMRs) have been a successful and integral tool in health care management. However, paper records are subject to incomplete filling, unclear handwriting, and incomplete and inconsistent data.[2,3] These limitations lead to medical errors that furthermore compromise the purpose of maintaining a record system. In addition, PMRs accumulate over time, requiring a large space for storage and archiving with no additional backup in case of natural disasters.[4,5]

Because PMRs remain standard in low- and middle-income countries (LMICs), patient care, surveillance, and medical research are often impeded. However, in the last 5 years, governments in LMICs, with help of the World Health Organization and other international nongovernment organizations, have advocated for and provided assistance in the development of electronic medical records (EMRs).[6-9] EMRs were sought to provide a longitudinal electronic record of patient medical information generated by 1 or more encounters at all levels of the health care delivery system that can be easily access and shared across multiple platforms. In sub-Saharan African countries like Tanzania, however, its utilization remains on a small scale, mostly limited to HIV clinics to maintain national HIV registries. As a result, limited research is available on medical records' quality and use in this part of the world. The few previous studies carried out in this field in sub-Saharan Africa focused on short-term implementations.[7] Tanzania is among many countries facing an increasing number of patients in need of long-term care and an ever-growing cancer population.[10] It is imperative to track and properly manage patients while using data provided by medical records to conduct etiologic, treatment/survivorship, and primary and secondary prevention research. The Ocean Road Cancer Institute (ORCI) is among the first major hospitals in Tanzania to implement an EMR system. The goal of implementation was to advance the quality of care of its primary patient population of cancer patients, lower administrative costs, improve surveillance, and enhance population health by providing data for medical research. These goals were derived after publications highlighted the benefits of the EMRs noted in high-income countries.[2,11,12]

Previous studies carried out in health systems in LMICs, however, have not showed the same level of success. Hence, it is not fully known to what extent EMRs

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Figure 1. Practice Variables

Demographic Information	Diagnostic Information	Treatment Information
• Name • Date of birth • Residence • Occupation • Sex • Religion • Tribe • Marital status • Follow-up contact information • Referral source/no. • Insurance status	• History of present illness • Past medical history • Family history • Social history • Liver/kidney panel • Full blood panel • Hormone receptor status • Histopathologic evidence/cytology/confirmed visual diagnosis • Ultrasound • Radiology report/CT • Investigation form/clinical notes/observation note • TNM staging • HIV status	• Hormone • Palliative • Neo-adjuvant/adjuvant therapy • Radiotherapy prescription • Chemotherapy prescription

may benefit health systems in sub-Saharan Africa. With increased emphasis of governments on using electronic data and communication systems, there is a need to investigate the extent to which EMRs have improved the completeness of available data. Thus, as a first step, the aim of this study was to compare completeness of patient demographic, diagnostic, and treatment information in PMRs vs EMRs.

Methods

This study was carried out between June and August of 2018 using PMRs and EMRs at ORCI, the only specialized cancer treatment hospital in Tanzania, located in the city of Dar es Saleem. Cancer patients begin treatment at ORCI after initial histopathologic confirmation or clinical diagnosis reserved for late-stage cases. ORCI keeps medical records for all patients treated by chemotherapy, radiotherapy, and palliative care and obtains copies of patient medical records from the referring hospitals before management. ORCI cares for approximately 2,500 cancer patients yearly. For simplicity, breast cancer patients were selected as the focus of this study.[13]

The EMR system, *INAYA*, was introduced at ORCI in June 2016 as a multimodule system to address patient care, pharmacy, accounting, billing, and human resources. Concurrently, PMRs were still being used as the standard at ORCI. The goal of maintaining this dual record system is to eventually phase out PMRs.

New patients are typically assigned a 6-digit case number, which is noted in the admissions logbook along with identifying patient data (patient name, date of birth, phone number, place of residence, insurance status, etc). The case numbers are subsequently used to open new patient case files in both the PMR and EMR. At the time of EMR implementation, both types of records were expected to be equally maintained by members of the health care team. Information technology (IT) staff were hired to provide enough training for providers in their separate departments.

Patients with a first-time diagnosis of breast cancer between January 2017 and April 2018 were included in this study. Case numbers were abstracted from logbooks and used to locate each patient PMR from the medical record storage facility and in the EMR system. To systematically assess the level of completeness, demographic, diagnostic, and treatment information was abstracted from both EMRs and PMRs.[14] The data were also stratified by insurance status to track trends of ORCI utilization.

Institutional review board approvals were obtained from the City University of New York, City College of New York, and the Ocean Road Cancer Institute, Dar es Saleem, Tanzania.

Statistical Analysis

Each medical record was thoroughly reviewed for the presence of variables identified in Figure 1. For each variable, the proportion of records with the desired information in the EMR were compared with that in the PMR. Additionally, for each variable, the patients were stratified by insurance type (public exempt vs national health insurance fund [NHIF]/private insurance) and the proportion of records for each variable recorded was compared. Data are summarized using frequency and percent with all statistical comparisons performed using McNemar test for paired proportions with exact P values computed when assumptions of the asymptotic χ^2 are not met. All statistical analyses were performed using SAS 9.3® (SAS Institute Inc).

Results

Using logbook records from January 2017 through April 2018, 376 primary breast cancer cases were abstracted for review. Of those, 328 records were found to be matching in both the EMRs and PMRs, with patient name being 100% matched. Among the demographic variables, there was near completeness in both record systems with at least approximately 90% of reviewed records containing that information (9/10 for EMRs; 7/10 for PMRs). Demographic

Table 1. Completeness of Medical Record by Type of Record			
	Electronic Medical Record	*Paper Medical Record*	*P Value*
Number of participants	328	328	–
Demographic Information			
Name (n, %)	328 (100.0%)	328 (100.0%)	–
Date of birth (n, %)	326 (99.4%)	327 (99.7%)	.56
Residence (n, %)	328 (100.0%)	324 (98.8%)	.13
Occupation (n, %)	323 (98.5%)	142 (43.3%)	< .001
Sex (n, %)	326 (99.4%)	326 (99.4%)	.999
Religion (n, %)	328 (100.0%)	310 (94.5%)	< .001
Tribe (n, %)	327 (99.7%)	295 (89.9%)	< .001
Marital status (n, %)	327 (99.7%)	146 (44.5%)	< .001
Follow-up contact Information (n, %)	322 (98.2%)	281 (86.1%)	< .001
Referral source (n, %)	167 (50.9%)	271 (82.6%)	< .001
Diagnostic Information			
History of present illness (n, %)	221 (67.4%)	276 (84.2%)	< .001
Past medical history (n, %)	199 (60.7%)	199 (60.7%)	.999
Family history (n, %)	177 (54.0%)	114 (34.8%)	< .001
Social history (n, %)	191 (58.2%)	164 (50.0%)	.031
Full blood panel (n, %)	27 (8.2%)	305 (93.0%)	< .001
Liver/kidney panel (n, %)	10 (3.1%)	307 (93.6%)	< .001
Histopathologic evidence/cytology/ confirmed visual diagnosis (n, %)	237 (72.3%)	307 (93.6%)	< .001
Receptor status (n, %)	111 (33.8%)	200 (61.9%)	< .001
Ultrasound (n, %)	194 (59.2%)	220 (67.1%)	.05
Investigation form/clinical notes/ observation note (n, %)	286 (87.2%)	318 (97.0%)	< .001
Radiology report (n, %)	176 (53.7%)	209 (63.7%)	.018
Tumor grade/staging (n, %)	95 (29.0%)	234 (71.3%)	< .001
HIV status (n, %)	33 (10.1%)	125 (38.1%)	< .001
Treatment and Management Information			
Neoadjuvant/adjuvant therapy (n, %)	148 (45.1%)	276 (84.2%)	< .001
Radiotherapy (n, %)	11 (3.4%)	119 (36.3%)	< .001
Chemotherapy (n, %)	198 (60.4%)	296 (90.0%)	< .001

information such as occupation, religion, tribe, marital status, and follow-up contact information was significantly better recorded in the EMR system. The PMRs, however, showed better documentation of referral source. There were no significant differences in the documentation rate for date of birth, residence, sex, and past medical history (Table 1).

Comparing diagnostic and treatment information showed that history of present illness, family history, social history, full blood panel, liver/kidney panel, histopathologic evidence, ultrasound, clinical note, radiology report, tumor grade/stage, HIV status, neoadjuvant/adjuvant therapy, radiotherapy, and chemotherapy were better documented in the PMR compared to EMR (Table 1).

Comparison for completeness was also assessed among public-exemption eligible patients covered under government programs (Table 2) and patients covered under the NHIF or those with other types of coverage including private insurance (Table 3). Records of 235 patients (71.6%) who were public-exemption eligible were available. For demographic information, there was a significant difference in completeness for occupation, marital status, and referral source, with the EMR better documenting these data. For diagnostic and treatment variables, the proportion of records with history of present illness, past medical history, social history, full blood panel, liver/kidney panel, confirmed diagnosis (histopathologic evidence), receptor

Table 2. Completeness of Medical Record by Type of Record—Public Exemption Patients

	Electronic Medical Record	Paper Medical Record	P Value
Number of participants	235	235	–
Demographic Information			
Name (n, %)	235 (100.0%)	235 (100.0%)	–
Date of birth (n, %)	233 (99.2%)	235 (100.0%)	.5
Residence (n, %)	235 (100.0%)	234 (99.6%)	.99
Occupation (n, %)	233 (99.2%)	97 (41.3%)	< .001
Sex (n, %)	234 (99.6%)	234 (99.6%)	.99
Religion (n, %)	235 (100.0%)	233 (99.20%)	.5
Tribe (n, %)	234 (99.6%)	230 (97.9%)	.13
Marital status (n, %)	234 (99.6%)	111 (47.2%)	< .001
Follow-up contact information (n, %)	230 (97.9%)	228 97.0%)	.56
Referral source (n, %)	103 (43.8%)	220 (93.6%)	< .001
Diagnostic Information			
History of present illness (n, %)	170 (72.3%)	195 (83.0%)	.006
Past medical history (n, %)	155 (66.0%)	131 (55.7%)	.02
Family history (n, %)	137 (58.3%)	66 (28.1%)	< .001
Social history (n, %)	149 (63.4%)	108 (46.0%)	< .001
Full blood panel (n, %)	24 (10.2%)	221 (94.0%)	< .001
Liver/kidney panel (n, %)	10 (4.3%)	222 (94.5%)	< .001
Histopathologic evidence/cytology/ confirmed visual diagnosis (n, %)	178 (75.7%)	226 (96.2%)	< .001
Receptor status (n, %)	70 (29.8%)	142 (60.4%)	< .001
Ultrasound (n, %)	146 (62.1%)	166 (70.6%)	.075
Investigation form/clinical notes/ observation note (n, %)	209 (88.9%)	231 (98.3%)	< .001
Radiology report (n, %)	125 (53.2%)	155 (66.0%)	.014
Tumor grade/staging (n, %)	67 (28.5%)	172 (73.2%)	< .001
HIV status (n, %)	25 (10.6%)	112 (47.7%)	< .001
Treatment and Management Information			
Neoadjuvant/adjuvant therapy (n, %)	113 (48.1%)	199 (84.7%)	< .001
Radiotherapy (n, %)	8 (3.4%)	86 (36.6%)	< .001
Chemotherapy (n, %)	139 (59.2%)	219 (93.2%)	< .001

status, clinical notes, radiology report, tumor staging, chemotherapy, and radiotherapy were significantly higher in the PMR compared to the EMR. There were no significant differences between the other variables (Table 2).

Ninety-three patients (28.4%) were covered under NHIF/private insurance. For demographic information, there was a significant difference in completeness for occupation, religion, tribe, marital status, and follow-up information, with the EMR better documenting these data. For diagnostic and treatment variables, the proportion of records with history of present illness, past medical history, social history, full blood panel, liver/kidney panel, confirmed diagnosis (histopathologic evidence), receptor

status, clinical notes tumor staging, chemotherapy, and radiotherapy were significantly higher in PMRs compared to EMRs. There were no significant differences between the other variables (Table 3).

Discussion

EMRs are truly an underresearched area in clinical medicine in sub-Saharan Africa. Data from this study provide insights into the completeness of patient information in the EMR system at ORCI, Tanzania where, like most LMICs, PMRs are still the standard. The mixed results highlight many of the challenges that can accompany EMR implementation in resource-restrained settings.[15]

Table 3. Completeness of Medical Record by type of Record – NHIF/Private Insurance			
	Electronic Medical Record	**Paper Medical Record**	**P Value**
Number of Participants	93	93	
Demographic Information			
Name (n, %)	93 (100.0%)	93 (100.0%)	–
Date of birth (n, %)	93 (100.0%)	92 (98.9%)	.99
Residence (n, %)	93 (100.0%)	90 (96.8%)	.25
Occupation (n, %)	90 (96.8%)	45 (48.4%)	< .001
Sex (n, %)	92 (98.9%)	92 (98.9%)	.99
Religion (n, %)	93 (100.0%)	77 (82.8%)	< .001
Tribe (n, %)	93 (100.0%)	65 (69.7%)	< .001
Marital status (n, %)	93 (100.0%)	35 (37.6%)	< .001
Follow-up contact information (n, %)	92 (98.9%)	53 (57.0%)	< .001
Referral source (n, %)	64 (68.8%)	51 (54.8%)	.05
Diagnostic Information			
History of present illness (n, %)	51 (54.8%)	81 (87.1%)	< .001
Past medical history (n, %)	44 (47.3%)	68 (73.1%)	< .001
Family history (n, %)	40 (43.0%)	48 (51.6%)	.22
Social history (n, %)	42 (45.2%)	56 (60.2%)	.031
Full blood panel (n, %)	3 (3.2%)	84 (90.3%)	< .001
Liver/kidney panel (n, %)	0 (0.0%)	85 (91.4%)	< .001
Histopathologic evidence/cytology/ confirmed visual diagnosis (n, %)	59 (63.4%)	81 (87.1%)	< .001
Receptor status (n, %)	41 (44.1%)	58 (62.4%)	.004
Ultrasound (n, %)	48 (51.6%)	54 (58.1%)	.4
Investigation form/clinical notes/ observation note (n, %)	77 (82.8%)	87 (93.6%)	.008
Radiology report (n, %)	51 (54.8%)	54 (58.1%)	.66
Tumor grade/staging (n, %)	28 (30.1%)	62 (66.7%)	< .001
HIV status (n, %)	8 (8.6%)	13 (14.0%)	.23
Treatment and Management Information			
Neoadjuvant/adjuvant therapy (n, %)	35 (37.6%)	77 (82.8%)	< .001
Radiotherapy (n, %)	3 (3.2%)	33 (35.5%)	< .001
Chemotherapy (n, %)	59 (63.4%)	77 (82.8%)	.001

NHIF, National Health Insurance Fund.

While documentation of demographic information was generally high in both systems, the EMRs best recorded the demographic information. Diagnostic, patient management, and treatment information, however, were not generally well documented in either system, the EMR much less.

The finding that demographic information was best documented in the EMRs was primarily driven by the system of information gathering at ORCI. Recordkeepers at the hospital collect and enter this information into the EMR and coexisting PMR file for every patient. Demographic information for the PMRs are collected on a form designated by the Tanzania Ministry of Health for ORCI. The form does not include prompts for occupation and marital status, thus resulting in inappropriate documentation of these variables by physicians in free-text notes where they were not always present. In contrast, the EMR provides relevant prompts where needed.

Diagnostic and treatment variables were better documented in PMRs compared to EMRs. A few factors may have contributed to this. First, ORCI is a tertiary hospital and, at this level of the health care delivery system, patient referrals are required from district hospitals before diagnosis and treatment can be initiated. The lack of availability of the EMR across the health systems and the lack of connectivity between the EMR systems, where available, renders the EMRs unreliable for patient information sharing

at this stage. Diagnostic tests, such as full blood panels and imaging, were only available in the EMR system, if they were performed at ORCI. PMRs, however, were better accessible since patients can bring prior laboratory work during a hospital visit. The laboratory reports are subsequently added to the patients' PMRs. Second, patients' laboratory results were not routinely uploaded to the system (eg, the full blood panel variable: PMR, 93.0%; EMR, 8.2%; $P <$ .001). Although most diagnostic laboratory tests besides imaging were performed at ORCI, they were routinely missing from the EMR. This may be a result of the system compatibility in the laboratory technology at ORCI or due to the limited manpower. Lastly, there were noticeably varying practices observed in the documentation of patient information. This may be related to the health care providers' willingness to adapt to the new system, or the nature of EMR/PMR data entry.

Lastly, lack of personnel and increased burden of paperwork per client for NHIF/private insurance patients may explain the decrease in diagnostic and treatment information when compared to public exempt patients. Financing for cancer care in Tanzania is guided chiefly by the cancer policy of the nation, which dictates free services for all persons with the disease. The largest proportion of patients are treated on this exemption basis (public exempt).[15] The other group of patients is covered by either the national health insurance (NHIF)—the default scheme for government employees—or private companies that take out one of various insurance policies for their employees.[16] This group additionally caters to patients that prefer to pay out-of-pocket, and foreigners, as they are not eligible for an exemption. With implementation of the EMR at ORCI, there had been a 2-phased approach, where the focus of the first phase was instituting it to the public exempt patients. As such, there were deliberate efforts to ensure that group took it up, more than the other group. Furthermore, the NHIF insured/private group required significantly more paperwork per client and therefore had gradual uptake into both systems.

Similar findings regarding low rates of EMR utilization were reported in Kenya, Ghana, and South Africa.[1,7,9] These studies highlighted the low user acceptance, increasing cost of maintenance, lack of full time IT expertise on staff, and automatic data and power backups as major factors that were debilitating to the system utilization. In 1 hospital, these issues resulted in the abandonment of their electronic systems in the emergency department.[7,9,17]

Unlike other studies, this is one of the first to audit an EMR system in sub-Saharan Africa, providing quantitative data on the state of EMR implementation. It is also the first to assess EMR documentation rates in cancer patients in Tanzania. A major strength of this study is the multitude and diversity of practice variables and the quantitative evidence in baseline data from both the EMRs and PMRs at ORCI. The study can aid in future direct investigations into the system and its barriers and opportunities for improvement. Another strength of this study was that it was conducted at the only cancer treatment hospital in Tanzania. The hospital provided the resources for a representative sampling as

patients travel from all over the country and neighboring areas to receive care. The quality of ORCI's paper medical records have been denoted in several published papers.[14,18,19]

Some limitations were evident. As this study is a retrospective review carried out at a single hospital using a single EMR interface, results may not be generalizable to other settings. Hence, more studies evaluating different EMR interfaces in sub-Saharan African are needed. This study was focused on early adoption and limited EMR data was available for analysis. The system is less than 2 years old and IT staff estimate that the EMR is only at 80% functionality. Computer availability, inconsistency in data collection, and not near 100% acceptance of the system by hospital staff, along with with the lack of connectivity between systems and the inability to effectively share necessary patient information electronically between hospitals, masked the true ability of the EMRs.

In summary, the applicability of evidence on EMR utilization arising from well-resources settings in the western countries like the United States, Canada, and Australia are not yet shown in Tanzania and the rest of sub-Saharan Africa.[20] Results from the evaluation of the EMR system at ORCI showed higher documentation rates of demographic information variables in the EMR when compared to the PMR. However, diagnostic and treatment information variables were better documented in the PMR. Recommendations to better improve EMR efficiency should include routine user satisfaction and input check surveys by EMR program designers to ensure EMR programs are functioning efficiently. This should include frequent updates to increase EMR compatibility with a variety of newer and available medical technology, and strengthening the IT staff to better train hospital staff to effectively use the system. Another important recommendation is to implement and link EMRs across all health systems in Tanzania. This can also involve developing a linkage between the EMR and the National Health Insurance Fund (NHIF) services and other health registries. Future research should focus on uncovering barriers and facilitators to EMRs' implementation and providers' attitudes towards EMR utilization across the health system, as well as implementing small-scale EMR systems in resource-restrained settings.

Acknowledgements

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How I Do It

Understanding Radiation Therapy:
A Primer for Tumor Registrars

Wilson Apollo, MS, RTT, CTR

Introduction

Radiation therapy has been an integral tool in the management of cancer since its early development with the discovery of the x-ray in 1895. Today, about 500,000 patients are treated with radiation therapy annually in the United States. Radiation therapy, in its multiple forms, is used widely for management of benign and malignant neoplastic conditions, as well as for palliative care. Palliative radiation therapy is among the best pain control tool for metastatic bone disease. But how does radiation therapy work? How does it interact with tissue when a patient is irradiated with photons or electrons?

Consider this article as a window into the complexity of radiation therapy, from the production of x-rays to the delivery of these focused beams of photons into malignant cells. It is but a glimpse into some of the many factors that must be considered when designing a treatment plan. It is not intended to be an exhaustive presentation of radiation therapy and treatment planning principles. Practitioners in these fields take years of training to master their skills. Lastly, it is not intended to provide any guidelines or recommendations on coding radiation therapy treatments.

Types of Radiation Therapy Delivery

Four major types of radiation therapy delivery include:
1. *Brachytherapy:* Isotope-based. Can be ultra-low-dose rate (ULDR), low-dose rate (LDR), or high-dose rate (HDR), generally delivered via radioactive seeds.
2. *Particle:* Proton, carbon, or heavy ion, with an increasing number of facilities nationwide providing this service.
3. *Cobalt-60–based:* Gamma rays (photons) such as the SRS Gamma Knife or Gamma Pod.
4. *Linear accelerator (Linac):* Photon-based technology (external beam radiation therapy [EBRT]), such as Tomotherapy, CyberKnife, X-Knife, SRT, 3D-CRT, IMRT, IGRT, and SBRT. Can also include electron therapy.

External Beam Radiation Therapy (EBRT)– Photon Therapy

EBRT involves the production of photons outside the patient (within a linear accelerator), which is then directed into the patient. The linear accelerator (Linac) remains the most widely used radiation therapy equipment worldwide for the delivery of EBRT. Most modern linacs can produce and deliver photon and electron therapy. When the treatment summary refers to a 6-mV photon energy, it is important to know that 6 mV refers to the maximum photon energy in the photon beam. A photon beam generated by a Linac has a spectrum of energies with the maximum photon energy of 6 or 12 mV, depending on the treatment prescription.

Figure 1. Schematic of a Linear Accelerator Photon Beam
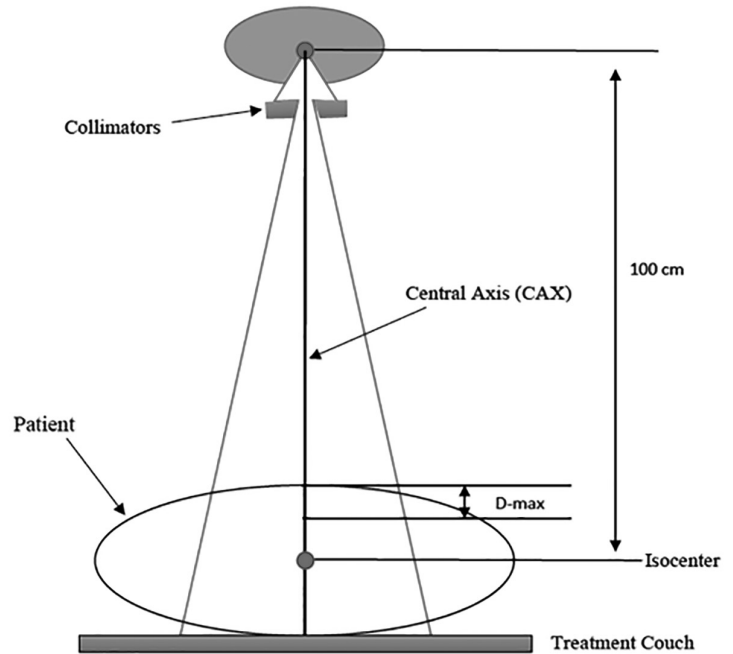
Linacs are calibrated to rotate about an imaginary point in space called the isocenter (Figure 1). The gantry housing where the photon beam exits the linac can rotate about the treatment couch 180° in either direction. The prescribed dose at a specified depth within the patient takes into account the distance from the source to the target volume (prescribed depth), the size of the treatment field, the number of fields used, the type of tissue it traverses (whether bone or air, as in the lungs), the proximity of organs at risk, the homogeneity, or, as is most often the case, inhomogeneity of the target volume, the inherent radiosensitivity of the various tissues in the path of the beam, the inverse square law, just to name but a few of the factors that impact directly on the final prescribed dose.

Figure 2 shows the STORE treatment planning techniques associated with EBRT.

External Beam Radiation Therapy-Electrons

Many linacs in used today in radiation oncology department nationwide can also deliver electron therapy. While photon therapy is very penetrating and most suitable for deep-seated tumor, in contrast, electron therapy is not very penetrating, which makes them suitable for treating superficial tumor or tumor beds, lymph nodes, chest wall, or lumpectomy scars. The average energy loss in tissue for a therapeutic electron beam is 2 MeV/cm with a very uniform dose deposition along its path. An important

Figure 2. STORE Treatment Planning Technique Codes Associated with EBRT

02: Photons
02: low energy x-ray, photons
03: 2D therapy
04: Conformal or 3D
05: IMRT
06: SRS, Radiosurgery, NOS
07: SRS, Radiosurgery, robotic
08: SRS, Gamma Knife
09: CT-guided online adaptive
10: MR-guided online adaptive

03: Protons
04: Conformal or 3D
05: IMRT (IMPT)
06: SRS, Radiosurgery, NOS

04: Electrons
03: 2D therapy
04: Conformal or 3D (think breast boost!)

Treatment Planning Techniques Associated with EBRT

concern when using electron therapy is the minimal skin sparing associated with it. In other words, electron therapy deposits far more radiation superficially (think skin dose), resulting in erythema in the clinical setting and, depending on the prescription, a more serious moist desquamation. In contrast, photon therapy provides a far more skin-sparing effect, particularly with higher energy photons. Table 1 provides a clearer picture of the skin-sparing effect of photon beams of differing energies.

Table 1. Skin-Sparing Effect of Photon Beams		
Beam Energy	*Depth of maximum dose (Dmax), cm*	*Skin Dose (%)*
Cobalt-60	0.5	50
6 MV	1.5	35
10 MV	2.5	25
18 MV	3.0	15

Consider a clinical case where a photon field needs to be matched to a different photon field or a previously irradiated field. Or consider matching a photon field to an electron field and we confront another set of factors that must be considered to ensure adequate coverage of a target volume. Inadvertent overlap of treatment fields can result in *hot spots*—regions where the dose exceeds the prescribed dose. Poorly matched fields can also have the opposite effect, creating *cold spots*—regions where the dose is less than that prescribed.

The use of proton (charged particle) therapy, approved by the US Food and Drug Administration in 1988, has gained greater momentum in the United States over the past decade. A major advantage of proton therapy over photon therapy is that the former can be manipulated to deliver nearly 100 % of the dose to a very specific depth, or narrow depth range, within the patient. This characteristic of proton therapy allows the delivery of therapeutic dose to target volumes in close proximity to organs at risk, while minimizing entry and exit dose. In contrast, photons reach a depth dose maximum at very shallow depth, depending on beam energy, while delivering dose along its entire path, until it exits the patient. Radiation oncologist and treatment planners have to account for entry and exit dose during the planning stages of a treatment prescription. The ever-present challenge of photon therapy is the delivery of therapeutic dose to the target volume, while minimizing dose to surrounding structures, particularly organs at risk. Inevitably, due to the nature of photons and their interaction with matter, healthy tissue, along the path of the photon beam, also receive a percentage of the prescribed dose. Both healthy and malignant tissue are damaged by radiation therapy, but dose fractionation allows for healthy tissue to recover more readily than malignant tissue.

Photon Interaction with Matter

Bremsstrahlung (Brem) radiation (Figure 3) is the primary interaction that occurs in modern linear accelerators (Linacs) to produce the photons that are then directed at the patient. In brief, the electron gun in a Linac generates a pencil-lead thin stream of electrons that is accelerated at a tungsten target. In the collision, the electrons interact with the nucleus of the tungsten target, resulting in the electrons rapid deceleration and direction change. This "braking" of electrons produces x-ray photons, which are subsequently used to target the tumor volume within the patient.

Compton interaction (Figure 4) is the primary interaction that occurs when photons interact with tissue within the patient.

Figure 3. Bremsstrahlung Radiation (Braking Radiation)

Electron
X-ray photon
Nucleus
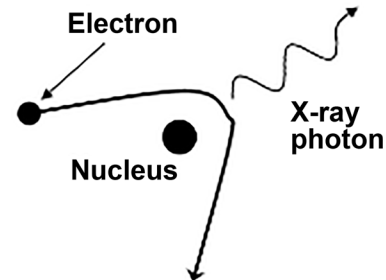
Figure 4. Compton Interaction

Compton Electron
Incident Photon
Scattered Photon
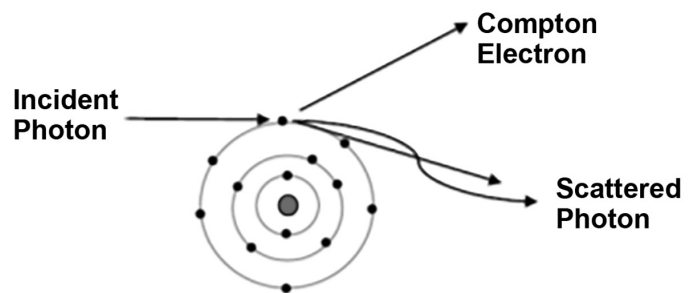
Photons from a linear accelerator (Linac) are more likely to interact with water molecules in tissue as these molecules predominate in the human body. This process is called *radiolysis*. The incident photon knocks out an outer electron, imparting some of its energy to the Compton electron, while the photon is scattered in a different direction. This interaction produces what is commonly known as *ion pairs*, the now positively charged atom and the negatively

charged electron that was knocked out of its outer valence shell. The photon always keeps some of its energy and can, in fact, continue to create additional ion pairs.

Ion pair production leads to the creation of free radicals (fragments of broken molecules) that carry an unpaired orbital electron in the outer shell, making it highly reactive. It is these free radicals that cause DNA damage to the targeted volume, namely the tumor/malignancy, and, ultimately, death of the cells. The Compton interaction with tissue is also known as the indirect effect of radiotherapy. In other words, the photons from the linac do not directly interact with the genetic material in the target volume. It is through the production of free radicals, the indirect effect, that tumoricidal dose is deposited in the target volume. In contrast to single-strand breaks, which are more numerous and easily repaired, double-strand breaks are more responsible for tumor destruction.

Direct and Indirect Action

In *direct action*, an ionizing particle (x-ray, gamma ray, electron, etc) interacts directly with the genetic material in the cell, leaving it in a chemically unstable state or causing its eventual destruction. With photon therapy, the direct action/effect plays a minor role in depositing lethal or potentially lethal doses to the target volume.

In *indirect action*, an ionizing particle interacts with the water molecules in tissue to form free radicals, which in turn interact with the genetic material in the cells. The indirect process causes most of the biological damage we see in the therapeutic range.

Radiation and Cellular Targets

There are critical targets in the cell that, if damaged, have a higher probability of resulting in irreparable damage or death of the cell. Studies indicate that the nucleus in the cell is more sensitive to radiation damage than the cytoplasm. Therefore, DNA is the most likely critical target for radiation action. It is important to note that much of the damage in DNA can be, and is, repaired by the cell, and all types of DNA damage are not equal in terms of their biologic significance. Radiation damage to DNA can be divided into 4 categories:

1. *Base damage:* Change or loss of a base; this is considered a type of mutation.
2. *Single-strand breaks (SSB):* Break in the backbone of 1 chain of the DNA molecule. These breaks are generally readily repaired by the cell, with little, if any, long-term consequence to the cell.
3. *Double-strand break:* Break in both chains of the DNA molecule. These breaks can have significant impact on the cell. It is more difficult for the cell to repair accurately. Double-strand breaks show a strong correlation with cell killing.
4. *Crosslinking:* Either within the DNA molecule (intrastrand) or from 1 molecule to another (DNA-interstrand or DNA-protein).

5 Rs of Radiobiology

Traditionally, radiation doses have been delivered in smaller portions (fractions) on a daily basis, or twice a day (BID). The rationale behind fractionation is neatly captured by what is known as the 5 Rs of radiobiology:

1. *Reoxygenation:* The more hypoxic the cell population, the more radioresistant they are. Fractionation allows cells to reoxygenate, making them more sensitive to the next treatment (fraction).
2. *Repair, DNA:* Fractionated treatment size results in reduced cell killing over single fraction treatment. However, fractionation allows for recovery of irradiated healthy tissue. Of note, mitosis has the least repair capability, with the S phase having the most repair capability.
3. *Radiosensitivity:* This factor recognizes the intrinsic radiosensitivity or radioresistance of certain cell population.
4. *Redistribution:* After standard fractionation, 200 cGy/ fx, there is a 5-fold increase in the death of cells in the most sensitive stage of the cell cycle compared with the most resistant phase. One would expect that the remaining cell population of radioresistant cells would render fractionation ineffective. However, this remaining population will redistribute into a more sensitive phase.
5. *Repopulation:* Cells in normal tissue and tumors respond to cell death caused by radiation by regenerating. Fractionation allows normal tissue to regenerate more rapidly over cancer cells.

Treatment Volume in Radiation Therapy

When planning radiation therapy treatments, defining the irradiated volume is critical. There are a number of definitions associated with irradiated volume that can assist the tumor registrar in understanding the primary tumor volume in question (Figure 5), particularly when regional dose and boost dose is delivered simultaneously. This is often the case with certain sites such as head and neck primaries.

Gross tumor volume (GTV) is the gross, palpable, visible or demonstrable extend and location of the malignant growth. The GTV extend can be assessed by various diagnostic imaging technologies, such as endoscopy, x-rays, computed tomography (CT), magnetic resonance imaging, positron emission tomography/CT, ultrasound, and bone scans. In addition, clinical examinations can provide additional information on the GTV.

Figure 5. Treatment Volumes in Radiation Therapy Planning

GTV: Gross tumor volume

CTV: Clinical tumor volume

PTV: Planned tumor volume
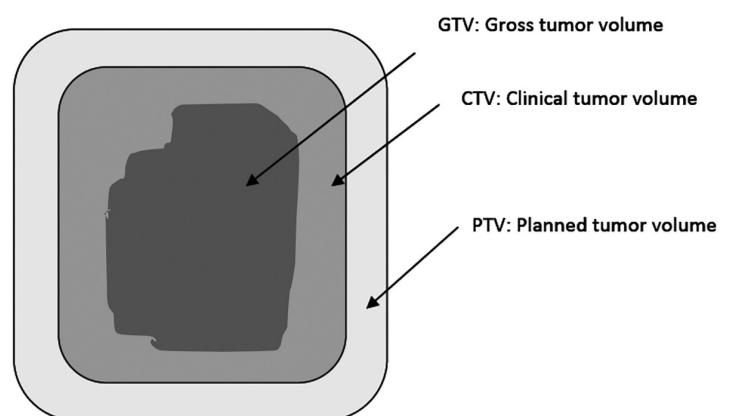
The *clinical target volume* encompasses the GTV and subclinical disease. Clinically, it includes the GTV and a safety margin around the GTV to consider any microscopic disease not readily detected.

The *planning target volume* (PTV) is a geometric concept used for treatment planning that considers additional factors to ensure that the target does indeed receive the prescribed dose. Among these factors are patient motion, organ motion, and the uncertainty of patient positioning during multiple treatments (fractions).

Organs at risk are normal structures within close proximity to the PTV that, due to their radiosensitivity and proximity to the target, can significantly alter the treatment planning approach and prescribed dose level. Organs at risk can lead to the use of multiple noncoplanar radiation beams to try to reduce the dose to these critical structures, particularly when treating with photon therapy.

Conclusion

In summary, the delivery of therapeutic radiation doses to malignancies is rather complex and requires extensive planning and sophisticated software and equipment to ensure a safe and effective delivery. Not only must we consider the patient, but we also factor in the safety of the personnel responsible for delivering radiation therapy. Numerous protocols have been developed over the years, based on clinical trials, to provide the best evidence-based treatment guidelines for treatment planning and delivery of radiation therapy. The challenge remains for tumor registrars to keep informed on basic principles of radiation therapy modalities and delivery technologies to ensure accurate coding of radiation therapy treatments.

Overcoming Survivorship Care Plan (SCP) Barriers: Creative Staffing Solution

Emma Bootle, MBA; Sonya Canavan, BS; Jody Plantz, MBA, CTR

Background

In looking at implementing treatment summary/survivorship care plan (TS/SCP) within the clinical setting, one of the barriers at UCHealth Cancer Care was insufficient staffing to prepare the TS/SCP. A TS/SCP can, on an uncomplicated patient, take 30 minutes to prepare, but on a complex patient can take hours. A research project at the University of Colorado Hospital found that it took an average of 81 minutes to prepare a treatment summary and care plan for breast cancer survivors.

Nationally, programs that are currently providing TS/SCPs are often doing so by having a midlevel provider or a registered nurse (RN) prepare the TS/SCP and conduct the survivorship visit. The oncology service line felt that this took valuable time from patient care and was not financially feasible, since there was no reimbursement for TS/SCP development.

Objective

A staffing model that would:
- Continue to meet/exceed Commission on Cancer (CoC) Standard 3.3
- Be cost-effective
- Keep the right staff performing patient care
- Provide consistent completion and delivery of SCP regardless of location

Results

In 2015, duties to complete the TS/SCP were transitioned to the cancer registry. The referral process was set up through the electronic health record by the in-basket function. Originally, the workload was distributed between multiple registrars. In the past few months, UCHealth was able to hire a dedicated staff person to complete the TS/SCP. The cancer registry technician (department support) currently creates the TS/SCP for 2 regions (including the National Cancer Institute facility) and will be onboarding our third and fourth region this fall.

Impact

Current staffing model:
- Meets CoC Standard 3.3 (Figure 1)
- Meets other accrediting organization's requirements
- Is cost-effective (Figures 2 and 3)
- Keeps the right staff performing patient care
- Provides consistent completion and delivery of SCP regardless of health care system region
- Utilizes registrar's knowledge of electronic medical record (EMR) and cancer registry software

Other benefits:
- Satisfied patients that are engaged in their follow-up
- Satisfied providers by stronger communication between care teams
- Increased referrals for supportive oncology (ie, clinical psychology and nutrition)
- Allows certified tumor registrars (CTRs) to work at the top of their scope, and have improved job satisfaction
- Allows cancer registry to be involved in patient care

Figure 1. Number of Completed Survivorship Care Plans per Year

2015: 528
2016: 805
2017: 998
2018: 1697 (YTD 2018 = 1053 | 2018 Annualized = 1697)
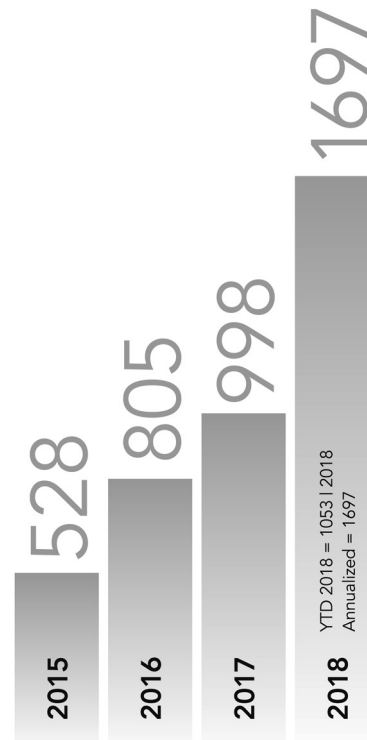
Figure 2. Hourly Rates Based on Title (Approximate Hourly Rates Based on Web Searches and Institutional Data)
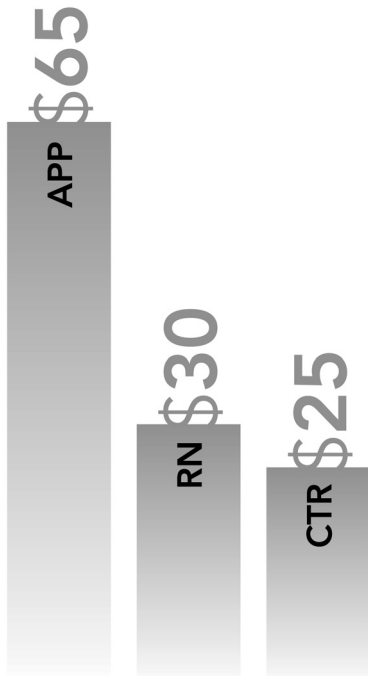
Figure 3. Newly Created Position Pays for Itself

2015:

APP: 1.35 hr x 528 SCP x 65 $/hr = $46,332

CTR: 1.35 hr x 528 SCP x 25 $/hr = $17,820

Cost savings per year of using a CTR vs an APP: $28,512

2018:

APP: 1.35 hr x 1,700 SCP x 65 $/hr = $149,175

CTR: 1.35 hr x 1,700 SCP x 25 $/hr = $57,375

Cost savings per year of using a CTR vs an APP: $91,800

The Impact of the Benign Brain Tumor Cancer Registries Amendment Act (Public Law 107-260) on Non-malignant Brain and Central Nervous System Tumor Incidence Trends

Bridget J. McCarthy, PhD[a]; Carol Kruchko[b]; Therese A. Dolecek, PhD[a]

Abstract: The study objective was to investigate patterns of reported non-malignant brain and CNS tumor incidence over a time period encompassing 1997-2008 during which time the Benign Brain Tumor Cancer Registries Amendment Act (PL 107-260) was passed and implemented. Analyses of 75,350 incident non-malignant brain and CNS tumors from eleven population-based central registries revealed that there were statistically significant increases in the age-adjusted incidence rate for non-malignant tumors for those diagnosed prior to 2002 and over the time period from 2002 until 2005. However, no significant change in the age-adjusted incidence rate for non-malignant tumors was observed over the time period 2005 to 2008 indicating that the incidence from this time period may quantify the "true" incidence of non-malignant brain and CNS tumors in the United States.

Key words: *brain, non-malignant, central nervous system, incidence, patterns*

Introduction

Brain and central nervous system (CNS) tumors are often devastating both in terms of morbidity and mortality and the importance of requiring the reporting of all primary brain tumors regardless of tumor behavior (malignant or non-malignant) has been recognized.[1,2] The Central Brain Tumor Registry of the United States (CBTRUS), in collaboration with participating state cancer registries, demonstrated in 1992 the feasibility of collecting data on all primary brain and CNS tumors in the United States[3] and has since promoted the collection of these data globally.[4] Passed in 2002, the Benign Brain Tumor Cancer Registries Amendment Act (Public Law 107-260; **ftp.resource.org/gpo.gov/laws/107/publ260.107.pdf**; accessed February 3, 2012) required central cancer registries supported by the National Program of Cancer Registries (NPCR) to expand data collection on primary brain and CNS cancer incidence to include tumors of non-malignant (benign and uncertain) behavior in addition to malignant behavior beginning with diagnosis year 2004. In keeping with the spirit which advocated for enactment of this law, other standard setters in surveillance including the Surveillance, Epidemiology and End Results (SEER) program and the North American Association of Central Cancer Registries (NAACCR) agreed to comply with the new statute. This united support enabled national public surveillance of the incidence and mortality of brain and CNS tumors.

Analyses of incidence data prior to diagnosis year 2004 in the United States have shown increasing trends over time for all primary and malignant primary brain tumors.[5-18] However, trends in the incidence of primary malignant brain tumors in more recent time periods have been flat or decreasing.[19,20] Significant changes in the coding, classification, and particularly, the ascertainment and reporting of brain tumors have occurred over the last 2 decades. Among the most significant of these changes was achieving consensus on the classification of the brain and CNS[21] and the efforts to reconcile the most recent coding and classification schemes, ICDO-3[22] and WHO 2000[21] which paved the way for a site definition to guide the collection of these tumors and a reporting scheme for comparing estimates of primary brain tumors across registries in 2000.[23] Although some cancer registries have routinely collected all primary brain and CNS tumors, the extent of collection and reporting of non-malignant tumors has not been consistent. These factors, along with implementation of Public Law 107-260, have undoubtedly influenced non-malignant primary brain and CNS tumor incidence patterns. Thus, the primary objective of this study was to evaluate patterns of reported incidence rates of non-malignant brain tumors diagnosed over a time period which spans the introduction and implementation of Public Law 107-260.

Methods

The Central Brain Tumor Registry of the United States (CBTRUS) has compiled population-based incidence data on all primary brain and CNS tumors, regardless of biologic behavior, since 1992. Data from 11 population-based state

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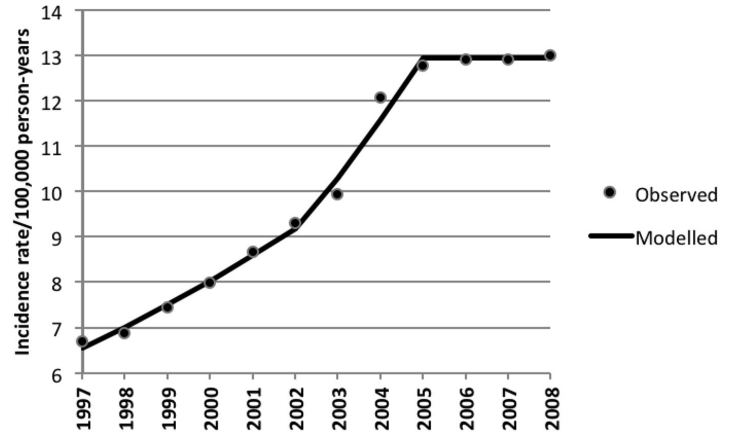
cancer registries (Arizona, Colorado, Delaware, Idaho, Maine, Massachusetts, Minnesota, Montana, North Carolina, New York, and Virginia) that collaborated with the CBTRUS and collected both malignant and non-malignant primary brain tumors diagnosed from 1997-2008 were analyzed. Representing close to 22% of the population in the United States, almost all of these central registries currently have achieved gold standard certification from NAACCR. Use of these data was approved by the University of Illinois at Chicago Institutional Review Board. Primary brain and CNS tumors were defined using the International Classification of Diseases for Oncology (ICD-O-3)[22] site codes of C70.0-C72.9, C75.1-C75.3 and C30.0 (histology codes 9522-9523). Non-malignant tumors were defined as those with ICD-O-3 behavior codes of "0" (benign) or "1" (uncertain).

Age-adjusted incidence rates and confidence intervals at the 95% level were calculated using SEER*Stat 7.0.9.[24] Population data available from the US Census Bureau were obtained from the National Cancer Institute Surveillance, Epidemiology and End Results (SEER) Program Web site (**seer.cancer.gov/popdata/**) to calculate incidence rates. Incidence rates per 100,000 were analyzed for each respective diagnosis year and were age-adjusted to the 2000 US Standard Population. To further investigate the potential for sharp changes in age-adjusted incidence rates over time, Joinpoint 3.5.2 (piece-wise regression) software was utilized.[25] Join points correspond to a point in time of a change in the trend where 2 different sloped lines come to a juncture, and the software fits the simplest join-point model that the trend data will allow. Using the grid search method, the permutation test model (model: $\ln[y]=xb$) assessed changes in age-adjusted incidence rates with a minimum number of 3 observations from a join point to either end of the data and a minimum of 3 observations between 2 join points. The annual percent change (APC) with corresponding 2-sided 95% confidence intervals (CI) for each trend segment was calculated with Joinpoint 3.5.2 software using weighted least squares regression.

Results

A total of 75,350 incident non-malignant brain and CNS tumors diagnosed from 1997-2008 were included in these analyses. A join-point analysis of the non-malignant brain and CNS tumor incidence over time revealed 2 junctures where the slope of the age-adjusted incidence rate trend line changed (Figure 1). Overall, a statistically significant increase in the age-adjusted incidence rate for non-malignant tumors diagnosed prior to 2002 was found (APC=7.0). During that time period, the age-adjusted incidence rate increased from 6.7 in 1997 to 9.3 per 100,000 person-years in 2002. A shift in the slope of the age-adjusted incidence rate trend was observed over the time period from 2002-2005, with a statistically significant increase in the non-malignant age-adjusted incidence rate (APC=12.2). The age-adjusted incidence rate during this time period increased more rapidly, from 9.3 in 2002 to 12.8 per 100,000 person-years in 2005. This shift in rates was primarily driven by the "jump" in age-adjusted incidence rates from diagnosis year 2003 (9.9 per 100,000 person-years) to diagnosis year 2004 (12.1

Figure 1. Trend in Age-Adjusted Incidence Rates for Non-Malignant Brain and CNS Tumors; CBTRUS 11 State Central Cancer Registries, 1997-2008

Incidence rates were per 100,000 and were age-adjusted to the 2000 US Standard Population. Analyses included data provided through the NPCR-CSS mechanism from state cancer registries in Arizona, Colorado, Delaware, Idaho, Maine, Massachusetts, Minnesota, Montana, North Carolina, New York, and Virginia.

Figure 2. Trends in Age-Adjusted Incidence Rates for Non-Malignant Brain and CNS Tumors by Gender, CBTRUS 11 State Central Cancer Registries, 1997-2008
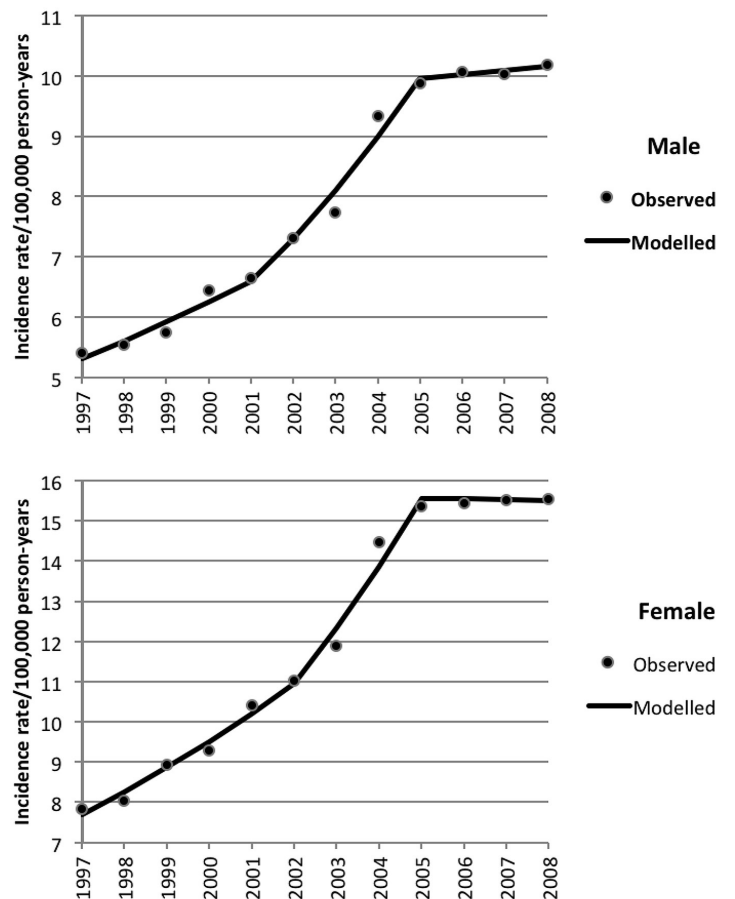
Incidence rates were per 100,000 and were age-adjusted to the 2000 US Standard Population. Analyses included data provided through the NPCR_CSS mechanism from state cancer registries in Arizona, Colorado, Delaware, Idaho, Maine, Massachusetts, Minnesota, Montana, North Carolina, New York, and Virginia.

per 100,000 person-years). As previously noted, diagnosis year 2004 was the first year mandated for implementation of the law. Conversely, no significant changes for non-malignant age-adjusted incidence rates were observed over the time period 2005-2008 (APC=0.0), with the rates slightly increasing from 12.8 in 2005 to 13.0 per 100,000 person-years in 2008.

A similar pattern was found in both males and females when analyzed separately (Figure 2). Males demonstrated changes in the slope of the age-adjusted incidence rate trend in 2001 and 2005, with a significant increase from 1997-2001 (APC=5.1), a larger increasing incidence from 2001-2005 (APC=10.8), and a flattening out of the incidence from 2005-2008 (APC=0.7). From 1997-2001, the age-adjusted incidence rate increased from 5.4 to 6.6 per 100,000 person-years, while from 2005-2008, the age-adjusted incidence rate for non-malignant brain tumors slightly increased in males from 9.9 to 10.2 per 100,000 person-years. The slope of the age-adjusted incidence rate trend in females significantly increased from 1997-2002 (APC=7.4), increased at a faster rate from 2002-2005 (APC=12.4), and showed no change in the age-adjusted incidence rate from 2005-2008 (APC=-0.2). From 1997-2002, the age-adjusted incidence rate increased from 7.8 to 11.0 per 100,000 person-years, while from 2005-2008, the age-adjusted incidence rate changed very little (15.4 to 15.5 per 100,000 person-years, respectively).

Discussion

The Benign Brain Tumor Cancer Registries Amendment Act (Public Law 107-260) has had a profound impact on non-malignant brain and CNS tumor incidence patterns in the United States. The study findings indicated substantial changes in non-malignant-specific reporting across the time period 1997-2008, particularly for the time period surrounding implementation of the law in diagnosis year 2004. A significant increase in the age-adjusted incidence of all primary and malignant brain and CNS tumors in the United States before the early 2000s has been noted by others.[5-16,18] Studies which have included data after this time period have reported flat or downward trends in the age-adjusted incidence of malignant brain tumors.[19,20] Many of these previous studies only included data on malignant brain tumors and those studies that did include non-malignant tumors reported data prior to diagnosis year 2004 and, therefore, do not reflect the impact of Public Law 107-260. Much of the large increasing trend in incidence of non-malignant brain tumors prior to 2004 was likely attributable to factors associated with refinement of standards, variable reporting requirements, and legislative inconsistencies that influenced case ascertainment. As mentioned previously, coding and classification changes for brain and CNS tumors were implemented during this time. Alternatively, some of the increase in incidence may be related to environmental exposures, diet, or other factors that could not be assessed in this data analysis.

The increasing trend in brain and CNS tumor age-adjusted incidence between 2002-2005 seen in this study is reminiscent of the increase in brain tumor incidence reported after the introduction of CT scans and MRIs.[11,12,14,15,27-29] This increasing trend in reporting of non-malignant brain tumor incidence most likely reflects many dynamic factors and an enormous amount of activity in the cancer registry community preparing for and adapting to the new legislation targeted for implementation in diagnosis year 2004.

Although the collection of non-malignant brain and CNS tumors was voluntary prior to 2004, among all CBTRUS collaborating state cancer registries, some actively collected data on non-malignant tumors, while others passively collected data on these tumors[30,31] At least 1 state cancer registry collected data on non-malignant brain tumors but did not collect data on non-malignant spinal cord tumors.[30] In addition, tumors that were not histologically confirmed may not have been required to be reported to the state cancer registry.[30] As a large percentage of non-malignant brain and CNS tumors are not histologically confirmed, but rather diagnosed by radiography or other non-invasive means,[31] this resulted in an underreporting of non-malignant tumors. It is apparent that data collected prior to 2004 significantly underestimated the true incidence of non-malignant brain tumors. It is likely that some continued under-reporting in the years directly following enactment of the law (eg, diagnosis year 2004) occurred as the state cancer registries worked to ensure reporting from all sources.

Looking at its data from 2004-2007, the NAACCR Data Use and Research Committee Data Assessment Work Group involving benign/borderline brain and ONS tumors reported at the NAACCR Annual Meeting in 2011 that incomplete data for non-malignant brain tumors are likely to be found in NAACCR central registries especially for states with low rate ratios and low rates for non-malignant brain tumors.[31] The possible underreporting of cases detected radiographically without microscopic examination has also been noted in a study of intracranial meningiomas in Denmark, Finland, Norway, and Sweden diagnosed between 1968-1997.[32] More recently, an 18% increase in reporting of non-malignant brain tumors through the use of electronic capture of radiology reports was reported by a single institution.[33]

The relatively constant non-malignant brain and CNS tumor incidence rates during 2005-2008 suggest stabilization in reporting under the Act's governance. Current collection of non-malignant brain and CNS tumors in the United States as reflected in diagnosis years 2004-2008 has been guided by Uniform Data Standards and under 1 federal law. State cancer registries are now required to actively collect data on all brain and CNS tumors (ICD-O-3 codes C70.0-72.9 and C75.1-75.3) regardless of behavior and method of diagnostic confirmation. Quality control measures to ensure complete ascertainment of brain and CNS tumors, especially non-malignant tumors, will continue to be essential.

In summary, under mandatory collection with standardized reporting requirements, it is believed that the reported age-adjusted incidence of non-malignant brain and CNS tumors in the United States is more closely reflecting the "true" incidence. Given the findings of the study, it should also be emphasized that any evaluation of trends in non-malignant or total brain and CNS tumors must be made cautiously, and only if a registry can satisfy the high-quality

standards for diagnosis years prior to implementation of the law in 2004. Trends in malignant brain and CNS tumors may be evaluated from earlier years depending upon the completeness of case ascertainment of the respective data set.

Acknowledgements

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Using an Existing Birth Defects Surveillance Program to Enhance Surveillance Data on Stillbirths

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Abstract: <u>Background</u>: Fetal death certificates (FDCs) are the main source of stillbirth surveillance data in the United States, yet previous studies suggest FDCs have incomplete ascertainment. In 2005, the Centers for Disease Control and Prevention (CDC) funded 2 pilot programs to determine the feasibility of expanding existing birth defects surveillance systems employing active casefinding methods to conduct surveillance of stillbirths. The objectives of this analysis were to: 1) estimate the completeness of ascertainment of stillbirths identified through one of the pilot programs, the Metropolitan Atlanta Congenital Defects Program (MACDP), and 2) compare the prevalence of stillbirths obtained through active casefinding (MACDP) with data available from FDCs. <u>Methods</u>: Stillbirths in metropolitan Atlanta were independently ascertained by both FDC and MACDP in 2006 and 2008. Capture-recapture methods were used to estimate the total number of stillbirths in the surveillance area. The sensitivities for capturing stillbirths were estimated for FDCs, MACDP, and both sources combined. Prevalence estimates for each data source and for the combined data sources were calculated using a denominator of live births plus FDC-identified stillbirths. <u>Results</u>: An estimated 1,118 stillbirths occurred in metropolitan Atlanta. MACDP captured 863 and FDCs captured 862. There were 198 stillbirths captured by MACDP and not reported by FDC, and 197 stillbirths identified by FDCs that were not initially captured by MACDP. The estimated sensitivities were 77.1%, 77.2%, and 94.8% for FDCs, MACDP, and both sources combined, respectively. The stillbirth prevalences for 2006 and 2008 using FDC data alone were 8.2 and 7.4 per 1,000 live births plus stillbirths, respectively, and 9.9 and 9.3 per 1,000 live births plus stillbirths, respectively, using both data sources combined. <u>Conclusions</u>: Leveraging the resources of existing birth defects surveillance programs in combination with FDCs could improve population-based ascertainment of stillbirths.

Key words: *birth defects, prevalence, sensitivity, stillbirth, surveillance*

Introduction

Stillbirth is an important public health concern. Despite improvements in prenatal and perinatal care in recent decades, stillbirth occurs in approximately 1 out of every 200 pregnancies and has a tremendous emotional and psychological impact upon families.[1,2]

Although reporting requirements vary, stillbirth is a reportable event in all 50 states as well as US territories. Data on stillbirths are regularly collected, analyzed, and reported by the National Center for Health Statistics (NCHS) through collaborative agreements with states as part of the National Vital Statistics System.[3] Based on these data provided to NCHS, in 2005 the prevalence of stillbirths in the United States was 6.22 per 1,000 live births plus stillbirths.[4] The use of vital records for surveillance purposes, however, has been problematic.[5-8] The American College of Obstetricians and Gynecologists (ACOG) has published recommended guidelines for conducting postmortem stillbirth evaluations.[9] However, several studies have shown that data on fetal death certificates (FDCs) not only yield inaccurate and incomplete information with respect to certain variables such as maternal health conditions, presence of a birth defect, and causes of death, but they also potentially underestimate the true prevalence of this event.[10-15] Without reliable population-based data, the conduct of epidemiologic studies of risk factors and causes of stillbirth are challenging.

In 2005, the Centers for Disease Control and Prevention (CDC) funded 2 pilot projects—1 in Iowa and 1 in metropolitan Atlanta—to assess the feasibility of expanding existing population-based birth defects surveillance programs to include surveillance of stillbirths with or without birth defects. The hypothesis was that using the infrastructure of established birth defects surveillance programs employing active casefinding methods to collect, analyze, and report data on stillbirths could enhance existing surveillance information on stillbirths. These enhancements would need to demonstrate improvements not only in the quantity and quality of information collected, but also completeness of case ascertainment. In 2008, Duke et al evaluated a revised data collection tool for use in the surveillance of stillbirths as part of the Metropolitan Atlanta Congenital Defects Program (MACDP).[10] After linking MACDP-identified stillbirths with FDCs, the analysis demonstrated that overall there was less missing information for critical variables, such as birth weight and fetal sex, compared with corresponding information on FDCs. Also, the amount and quality of clinical and pathological information abstracted

from the medical record through MACDP surveillance was improved and could potentially allow for a better understanding of the contributing factors associated with the fetal death. The current paper reports the results of a follow-up study; the objectives were to evaluate the completeness of case ascertainment and compare prevalence of stillbirths identified through MACDP, FDCs, and both data sources combined for the years 2006 and 2008.

Methods

Pregnancy Outcome Determination

Pregnancy outcome classification was based on the definitions for live birth, fetal death, and induced termination of pregnancy provided by the 1992 Revision of the Model State Vital Statistics Act and Regulation (Model Law, page 2).[3] There is no universally accepted definition of stillbirth that includes the criteria for gestational age or birth weight. For surveillance purposes, stillbirth was defined by MACDP as a fetal death occurring at 20 or more weeks of gestation or 350 or more grams if the gestational age is not known. The gestational age used was the age of the fetus as indicated by the physician in the medical record. Lastly, the Model Law defines an induced termination of pregnancy as "… the purposeful interruption of an intrauterine pregnancy with the intention other than to produce a live born infant and which does not result in a live birth and … excludes management of prolonged retention of products of conception following fetal death." While fetal heart tones may be present and documented in the medical record prior to the induction of labor, the "intention" is not always clear; therefore, assessing misreporting of these outcomes as fetal deaths is problematic. For MACDP stillbirth surveillance purposes, these cases are ascertained and reported as stillbirths resulting from medical intervention along with the indication for induction of labor (Figure 1).

Case Ascertainment

Stillbirths were independently ascertained though FDCs provided by the state of Georgia and MACDP. Georgia requires all fetal deaths to be reported if brought to the attention of a health care provider; more information on fetal death registration requirements in Georgia can be found in Chapter 31 of the Official Code of Georgia (O.C.G.A § 31-10-18). Prior to 2006, MACDP received FDCs on an ongoing basis as 1 data source for ascertainment of birth defects; however, due to an administrative lapse, FDC for 2006 and later were not obtained until late 2009, allowing for the independence of sources in casefinding for the current assessment. A complete file of FDCs for 2007 was never obtained, necessitating the exclusion of that year from this analysis.

MACDP is a population-based active surveillance system ascertaining structural and chromosomal anomalies among pregnancies resulting in a live birth, stillbirth, or termination. Trained medical records abstractors visit area birthing hospitals, pediatric hospitals, and other clinical providers including prenatal diagnostic centers and genetics clinics located in the 5 central counties of metropolitan

Figure 1. Schematic Used by MACDP for Case Classification of Outcome
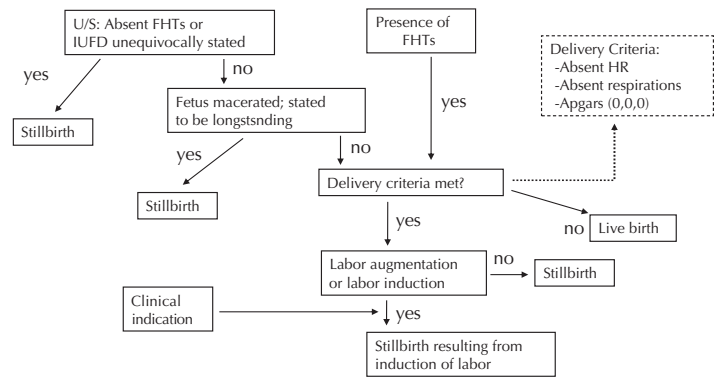
FHTs, fetal heart tones; HR, heart rate; IUFD, intrauterine fetal death; MACDP, Metropolitan Atlanta Congenital Defects Program; U/S, ultrasound.

Atlanta to identify and abstract information on potential cases. In 1994, MACDP abstractors began to visit the outpatient offices of area perinatologists and maternal–fetal medicine specialists to abstract information about pregnancies diagnosed prenatally with congenital abnormalities.[16] Clinical reviewers review each potential case and determine eligibility for inclusion in the surveillance system and code the birth defects. MACDP methods for birth defects surveillance have been previously described.[17,18] In 2006, after revisions to the data collection tool and surveillance methods, MACDP began active surveillance for all stillbirths, with or without birth defects. The sources for active ascertainment of stillbirths by MACDP largely overlapped with the sources for birth defects ascertainment but included a few additional sources such as emergency department records and autopsy and placental histopathology reports. In addition, mothers diagnosed with an intrauterine fetal death at 20 or more weeks of gestation in the specialty clinics previously mentioned were also ascertained with follow-up attempted at the delivering hospital. Stillbirths which occur without any resulting contact with a health care provider (eg, no emergency department visit, hospitalization, or visit to selected Atlanta-area prenatal care providers) are not able to be ascertained by MACDP. Furthermore, MACDP does not have access to abortion clinic records and any stillbirths or terminations occurring at such facilities would be missed.

Live birth certificates and FDCs for 2006 and 2008 were obtained from 2 departments within the Georgia Department of Public Health. In 2006, data came from the Office of Health Indicators for Planning and in 2008 from the Office of Vital Statistics. The records of stillbirths identified through MACDP were linked to FDCs for the same birth cohorts (2006 and 2008) by means of a deterministic matching process with multiple iterations using the following variables: mother's name and race, father's name, gender of fetus, date of event, hospital, county of residence, and mother's address at the time of delivery. Manual matches were also attempted for stillbirths that did not link. For those stillbirths in the FDC that did not link to a stillbirth in MACDP, abstractors were asked to locate

Table 1. Fetal Deaths Reported by Gestational Age, Georgia and Metropolitan Atlanta, 2006 and 2008

| | Georgia | | | | Metropolitan Atlanta | | | |
| | 2006 | | 2008 | | 2006 | | 2008 | |
Gestational age	N	%	N	%	N	%	N	%
< 20 weeks*	6,894	71.9	5,061	62.1	3,159	78.2	2,208	65.1
≥ 20 weeks	1,141	12.6	1,111	13.4	474	11.7	459	13.5
20–27 weeks	722	4.6	652	7.9	305	7.6	279	8.2
28 + weeks	419	6.8	459	5.5	169	4.2	180	5.3
Missing	985	2.5	2,092	25.3	405	10.0	724	21.4
Total	**9,020**	**100**	**8,264**	**100**	**4,038**	**100**	**3,391**	**100**

*Fetal deaths before 20 weeks of gestation, also known as miscarriages or early fetal losses, were not considered in this analysis.

2006 data were from Georgia Department of Public Health, Office of Health Indicators for Planning.

2008 data were from Georgia Department of Public Health, State Office of Vital Records.

Table 2. Distribution of Stillbirths by Source of Identification and Estimated Total Stillbirths in Metropolitan Atlanta, 2006 and 2008

| | | Identified by MACDP | | |
		Yes	No	Total
Identified by FDC	Yes	665	197*	862
	No	198	(58)**	256
	Total	863	255	(1,118)

MACDP, Metropolitan Atlanta Congenital Defects Program; FDC, fetal death certificates.

*Includes 30 stillbirths for which no medical record could be found and 26 that were delivered in a county outside MACDP catchment area.

**Estimated stillbirths missed by both sources.

the medical records for those stillbirths and abstract the relevant information if the mother was a resident of the 5-county surveillance area.

Data Analysis

To evaluate the total number of stillbirths occurring among the surveillance population and the relative contribution of each data source for casefinding (active surveillance through MACDP; passive surveillance through FDC), capture–recapture methods were used.[6,19,20] Briefly, this method can be used to estimate total prevalence and to evaluate the relative contribution of independent case sources. The number of stillbirths missed by both sources was estimated by the product of the number missed by each source, divided by the number identified by both sources. These stillbirths missed by both sources were then added to the total number identified by either source to estimate the total prevalence. The prevalence of stillbirths was then calculated by each data source alone as well as for both data sources combined. Estimates were also calculated including and excluding stillbirths resulting from induction of labor as a medical intervention. The denominator for all prevalence estimates included live births plus stillbirths from vital records restricted to the 5-county area as recorded in vital records. Using a normal approximation, 95% confidence intervals were calculated for all estimates of prevalence,

as well as for the sensitivities and specificities of each data source alone and the data sources in combination.

Results

In 2006 and 2008, there were 2,252 stillbirths reported in the state with just under half of these occurring among mothers residing in the 5-county metropolitan Atlanta area (Table 1). Because Georgia law requires that all fetal deaths be reported regardless of gestational age if brought to the attention of a health care provider, the majority of fetal deaths in Georgia are losses before 20 weeks of gestation (Table 1). The year 2008 had substantially more fetal deaths with a missing gestational age than the year 2006 because of differences in data sources from the state. The data from 2006 from the Office of Health Indicators for Planning had missing clinical estimates of gestational age recoded as the gestational age based on the last menstrual period, if available. The data from 2008 were the raw vital statistics data that did not undergo this assignment process.

MACDP captured 863 stillbirths and FDCs captured 862. Of these, 665 stillbirths were independently captured by both sources (Table 2). MACDP captured an additional 198 stillbirths for which no FDC could be found. Similarly, a total of 197 stillbirths were identified based soley on the FDC for casefinding (Table 2). These cases would have been missed if FDC had not been available for retrospective casefinding and abstraction. Using capture–recapture methods, 58 stillbirths were estimated as missed by both sources ([198 × 197]/665 = 58), resulting in 1,118 total stillbirths (95% confidence interval [CI], 1,052–1,183) in metropolitan Atlanta during 2006 and 2008. The estimated sensitivities for capturing a stillbirth were 77.1% (95% CI, 74.7%–79.7%) for FDC alone, 77.1% (95% CI, 74.7%–79.7%) for MACDP alone and 94.8% (95% CI, 93.5%–96.1%) for both sources combined. Of the 197 stillbirths identified solely through FDC, medical records were sought but not found for 30 of them, and 26 additional stillbirths occurred among mothers who resided within the catchment area, but delivered in a facility outside of it. The medical records for these 26 stillbirths were not sought by MACDP.

Table 3. Distribution of Stillbirths by Pregnancy Outcome, Initial Source of Identification, and Linkage Status, Metropolitan Atlanta, 2006 and 2008

| | Linked | | Did Not Link | | |
| | Identified by | Identified by | Identified by | Identified by | |
Pregnancy Outcome	MACDP	FDC	MACDP	FDC	Total
Stillbirth with birth defect	82	4	17	0	**103**
Stillbirth without birth defect	520	130	139	2	**791**
Stillbirth due to induction of labor for birth defect	31	0	30	0	**61**
Stillbirth due to induction of labor for other pregnancy complication*	32	5	12	0	**49**
Total	**665**	**139**	**198**	**2**	**1,004****

FDC, fetal death certificate; MACDP, Metropolitan Atlanta Congenital Defects Program.

*Complications such as chorioamnionitis, premature rupture of membranes, and pre-eclampsia

**Does not include 30 stillbirths for which no medical record could be found and 26 that delivered in a county outside MACDP catchment area

Table 4. Reasons for Excluding Stillbirths Identified Through Fetal Death Certificiates as Occurring at 20 or More Weeks of Gestation, Metropolitan Atlanta, 2006 and 2008

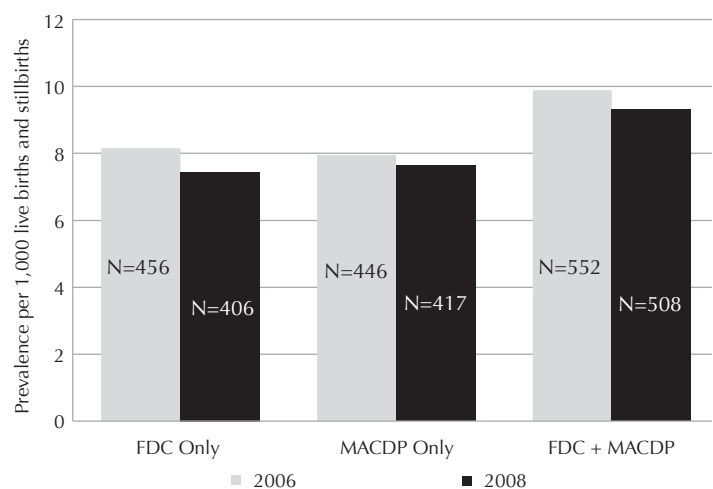| Reason for Exclusion	N	(%)
Medical record indicated less than 20 weeks*	45	(39.5)
Duplicate FDC	34	(29.8)
Live birth	20	(17.5)
Non-resident**	13	(11.4)
Wrong year of FDC	2	(1.8)
Total	**114**	**(100)**

FDC, fetal death certificate.

*Medical record review clearly indicated the death occurred prior to 20 weeks of gestation indicating that the death was misclassified as a death occurring at less than 20 weeks on the FDC.

**Medical records documented these mothers as not residing in the metropolitan-Atlanta surveillance catchment area.

Figure 2. Prevalence of Stillbirths by Data Source, Metropolitan Atlanta, 2006 and 2008

FDC, fetal death certificate; MACDP, Metropolitan Atlanta Congenital Defects Program.

Furthermore, MACDP captured 61 stillbirths for which induction of labor was performed due to the fetus being affected by a birth defect. Of these, 31 linked to FDC and 30 could not be linked. MACDP ascertained another 49 stillbirths for which induction of labor was performed secondary to a pregnancy complication such as preeclampsia, premature rupture of membranes, or chorioamnionitis. Thirty-seven of these were issued a FDC and 12 did not link (Table 3). The 30 cases for which the medical record could not be found and the 26 cases that were delivered outside the catchment area are not included in the assessment of ascertainment by pregnancy outcome reported in Table 3.

Lastly, there were an additional 114 stillbirths identified through FDC with a gestational age of 20 or more weeks that were subsequently excluded after reviewing the medical record. The reasons for excluding these cases are listed in Table 4. Forty-five cases were excluded after review of the medical record clearly indicated that the death

occurred before 20 weeks of gestation. Thirty-four cases were singleton stillbirths for which 2 identical FDCs were generated. Twenty cases had medical record documentation that the fetus was born alive and expired shortly after birth. Another 13 cases were excluded because the mother did not reside in the surveillance catchment area and 2 cases had the wrong year of birth on the FDC.

There were 55,707 and 54,581 live births and stillbirths (the stillbirths in the denominator were based on the number ascertained by FDC) delivered in the metropolitan Atlanta surveillance area in 2006 and 2008, respectively. Using only those stillbirths identified from FDCs, the prevalence of stillbirth was 8.2 per 1,000 live births plus stillbirths in 2006 (95% CI, 7.4–8.9) and 7.4 per 1,000 live births plus stillbirths in 2008 (95% CI, 6.7–8.2). Using only ascertainment by MACDP, the estimates were 8.0 and 7.6 per 1,000 live births plus stillbirths (95% CIs, 7.3–8.7 and 6.9–8.4), respectively. Using both sources for ascertainment yielded estimates of 9.9 and 9.3 per 1,000 live births plus

Figure 3. Prevalence of Stillbirths With and Without Those Resulting from Induction of Labor, Metropolitan Atlanta, 2006 and 2008
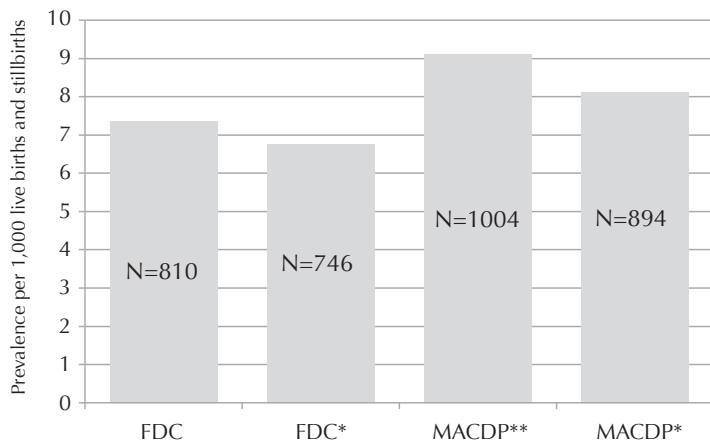
*Excludes stillbirths occurring after induction of labor.
**MACDP numerator includes stillbirths identified through FDC and linked (n = 139)
FDC, fetal death certificate; MACDP, Metropolitan Atlanta Congenital Defects Program.

stillbirths (95% CIs, 8.1–10.7 and 8.5–10.1), respectively (Figure 2). Prevalence estimates were compared including and excluding stillbirths occurring after induction of labor as a medical intervention (Figure 3). Excluding stillbirths occurring after induction of labor naturally reduced the prevalence; we observed a greater reduction for MACDP identified stillbirths than FDC-identified stillbirths.

Discussion

The use of FDC alone for population-based surveillance of stillbirths is limited, and uncertainty about the utility of FDC data for risk-factor analysis has been previously noted.[7,10-12] Complete and reliable surveillance data is needed if hypothesis-driven epidemiologic studies are to be conducted. The current study demonstrated that expanding the capabilities of an existing birth defect surveillance system to include active ascertainment of stillbirths, and combining that information with what is gathered from FDCs, is feasible and results in the ascertainment of cases that would have otherwise been missed by either system alone. Expanding MACDP to include surveillance of stillbirths required a few modifications to the birth defects surveillance protocol, such as accessing emergency department records (to capture cases arriving as an emergency and potentially getting discharged without hospital admission), and autopsy and placental histopathology information. There was no additional staff required to implement stillbirth surveillance as sources for casefinding overlapped with sources already used for birth defects surveillance and were already being reviewed by clinical abstractors.

Each data source—FDC and MACDP—has limitations. The current analysis, as well as previous studies, indicate that FDCs underreport stillbirths, as well as often misreport the pregnancy outcome and contain large amounts of missing information for critical variables such as gestational age, birth weight, and cause of death.[10,18] With respect to cause of death, this may in part be explained by the fact that the majority of FDCs are completed before all postmortem evaluation information is available.[21] For MACDP, our analyses suggest that a large number of stillbirths would have been missed if not for the availability of FDCs as a source for casefinding. Routine procedures for MACDP normally involve obtaining FDC on a monthly basis, from which stillbirths can be identified on an ongoing basis. This was not the case for our study years, allowing for the application of capture–recapture methods to estimate the number of stillbirths occurring in the surveillance population. Active ascertainment by MACDP was only able to collect what was available from the medical record. However, when both MACDP and FDCs were used together, they ascertained more stillbirths than either system captured independently. The factors influencing case ascertainment within each data source are not clear. The underascertainment of stillbirths is not likely a random event; it may be associated with factors such as maternal race/ethnicity, gestational age, delivery facility, or the cause of death, or perhaps factors that are not even recorded. More analyses need to be undertaken to better understand the role that these factors may play in the ascertainment of stillbirths. This could provide potentially valuable information to inform training needs and strategies to improve the reporting process.

Active casefinding of stillbirths has several strengths. Trained abstractors visit area hospitals, locate medical records for potential cases, and record the relevant information. The abstracted information for each potential stillbirth is systematically reviewed by 1 or more MACDP clinicians to ensure that inclusion criteria are met and to designate the appropriate outcome classification. Previous studies by Duke et al, using data from MACDP, have demonstrated that active ascertainment and medical chart review improves upon the quantity and quality of the data collected.[10,22] In addition, the in-depth medical record review resulted in more accurate classification of pregnancy outcomes, which provided insight into the potential misclassification of pregnancy outcomes by FDCs. This information is important to better understand stillbirth prevalence estimates that are based on FDCs alone. Active ascertainment can allow for the inclusion or exclusion of stillbirths resulting from the medical induction of labor or stillbirths that were actually live births. As shown in Table 3, about 50% of the inductions performed for a fetus affected by a birth defect linked to a FDC, whereas about 75% of those inductions performed for other pregnancy complications were issued a FDC. It is not possible to know if the cases that did not link were issued an induced termination of pregnancy (ITOP) certificate, data which are deidentified and unlinkable with information from other sources. Anecdotally, the majority of inductions performed in the setting of a fetus affected by a birth defect are done subsequent to the administration of intrauterine potassium chloride, and identifying these events through the review of medical records is relatively straightforward. Therefore, from a surveillance perspective, the intent of the procedure is apparent, and ITOP certificate should have been issued. However, many of these birth defects can be

considered lethal anomalies and should be considered when understanding fetal mortality rates. On the other hand, inductions performed in the context of other clinical scenarios, such as severe chorioamnionitis, are most often conducted in the best medical interest of the mother and the intent may very well have been to produce a live birth. It is likely that these clinical situations explain the differences in whether a FDC was issued or not. Active casefinding allows for these events to be captured and documented based on the thorough review of medical records, potentially improving our understanding of the impact of these events on estimates of the prevalence of stillbirths. These distinctions cannot be made when using FDC data alone.

We capitalized on a lapse of availability of FDCs to MACDP for case ascertainment. Having 2 independent data sources for stillbirth ascertainment allowed us to conduct a capture–recapture analysis to estimate the total number of stillbirths occurring within metropolitan Atlanta, and the number potentially missed by the 2 data sources working independently. This normally cannot be done when FDCs are obtained and used on an ongoing basis as a source for casefinding.

This analysis is subject to several limitations, however. First, we were limited to only 2 years of data; a similar analysis is planned for stillbirths occurring in 2009 and later. Second, we did not assess or compare data quality between sources, an important next step to further demonstrate the utility of this approach to stillbirth surveillance. Third, it was not possible or practical to capture every fetal death. Stillbirths that occurred to mothers residing in metropolitan Atlanta but delivering outside the catchment area were missed by MACDP and were therefore not subjected to medical chart review. However, they could be identified if issued a FDC and were included in the analysis as shown in Table 2. Similarly, medical records for terminations and stillbirths delivered at abortion clinics are not accessible by MACDP. Lastly, it is not clear why such a large number of medical records could not be located (n = 30). This may reflect inadequate staffing and resources to conduct an exhaustive search for the medical record as many health care facilities store medical records offsite after a certain length of time.

Fetal death reporting by states to the National Vital Statistics System is and will remain the core infrastructure for stillbirth surveillance in the United States; however, expanding existing birth defects surveillance programs to include active ascertainment of stillbirth is potentially a valuable approach to help address our current knowledge gaps about the frequency and risk factors for stillbirths. More importantly, improvements to surveillance data on stillbirths will require multidisciplinary efforts to increase and standardize the use of ACOG recommended clinical guidelines for postmortem stillbirth evaluation.

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Journal of Registry Management Continuing Education Quiz—FALL 2019

SUMMARY OF VETERANS HEALTH ADMINISTRATION CANCER DATA SOURCES

After reading this article and taking the quiz, the participants will be able to:
- Describe the Veterans Health Administration (VHA) data sources available for cancer-related research.
- Understand the advantages and disadvantages of each data source.
- Describe examples of published cancer research using each data resource.

1. Which VHA data source has been MOST commonly used by the VHA for cancer-related research?
   a) VA Central Cancer Registry
   b) Facility Oncology Survey
   c) CDW-Oncology Raw Domain
   d) VA Cancer Care Cube

2. All of the following are VHA-defined data elements that the VA Cancer Registry Systems collects EXCEPT:
   a) Sexposure to ionizing radiation.
   b) exposure to asbestos.
   c) exposure to secondhand smoke.
   d) branch of military service.

3. Which software program is used by VHA medical centers to perform abstracting and follow-up?
   a) Rocky Mountain
   b) OncoTraX
   c) VistA Imaging Display
   d) Pyramid platform

4. According to Table 2, which data source has the advantage of creating reports and cross-tabulations without the need to write SQL queries?
   a) VA Central Cancer Registry
   b) Facility Oncology Survey
   c) CDW-Oncology Raw Domain
   d) VA Cancer Care Cube

5. The CDW-Oncology Raw Domain and the VA Cancer Care Cube data may be a useful source for which of the following activities?
   a) Case ascertainment and prospective recruitment
   b) Case identification of older cases
   c) Estimating cancer incidence
   d) Evaluating cancer survival

6. Select the unique additional VHA data source for monitoring facility performance to determine areas for quality improvement.
   a) Epidemiology of Cancer among Veterans (EpiCAN)
   b) External Peer Review Program (EPRP)
   c) Facility Oncology Survey
   d) Cancer Care Cube

7. According to Table 2, data aggregation and error checking are a strength of which data source?
   a) CDW-Oncology Raw Domain
   b) VA Cancer Care Cube
   c) Corporate Data Warehouse
   d) VACCR

8. Which of the following describes the 2 types of reporting delays across cancer registries?
   a) The time between receipt of a cancer dx and case reportability
   b) The time in which the data becomes available to uses is considered
   c) The time between date of diagnosis and date of first treatment
   d) The time between casefinding and abstract completion

9. Which description is notable for CDW-Oncology Raw Domain data?
   a) Data collection is not as timely as automated sources
   b) Mostly clean data
   c) Prone to including suspected cancers
   d) Robust quality

10. Which of the following was identified by the Facility Oncology Survey, administered by the Healthcare Analysis and Information Group (HAIG)?
   a) Survival analysis
   b) Resource availability for delivery of cancer care
   c) Diagnostic evaluations
   d) Treatment patterns

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