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Berkeley, California 94704

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13. ABSTRACT *(Maximum 200*

The purpose of this project is to enhance the value of the California Cancer Registry as a research tool for clinicians and epidemiologists interested in conducting breast cancer research. The objectives of the projects are to: (1) classify breast cancers according to the major staging schemes currently in use in the U.S.; (2) increase the amount of treatment data for breast cancer; and (3) link breast cancer case data with other data bases to improve survival information and collect co-morbidity information. During the past year physician follow back for additional treatment data was initiated statewide. Linkage with the state's breast cancer screening and Medicaid programs was accomplished. Linkage with hospital discharge files was completed. In the past year the project generated two oral and one poster session presentation at professional meetings, one publication, and one draft manuscript.

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William E Wright 1/25/93
PI - Signature Date

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INTRODUCTION

The purpose of this project is to enhance the value of the California Cancer Registry (CCR) as a research tool for clinicians and epidemiologists interested in conducting breast cancer research. The goals are to code in greater detail the extent of disease at the time of diagnosis, to gather complete information about the first course of treatment, to collect follow-up information about vital status, to code information about occupation and industry, to link the CCR files with a variety of existing files containing information on patterns and costs of care, and to develop mechanisms by which a wide audience of breast cancer researchers can obtain access to the CCR database.

BODY

Progress to date:

Objective 1 - Code SEER Extent of Disease for all breast cancers diagnosed in California starting with January 1, 1988.

Between 1988 and 1993 all breast cancers were staged according to the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) Program Summary Staging Guide (1), basically a classification of cases into *in situ*, localized, regional, and distant disease. In 1994 the CCR changed its reporting requirement from the SEER Summary Stage to the SEER Program's Extent of Disease (EOD) (2) classification scheme in order to be able to apply a computer program available from the NCI to classify breast cancer cases into the TNM classifications and the Staging Categories (0, I, II, III, IV) of the American Joint Committee on Cancer (AJCC) (3). A major objective of this award has been to reclassify all breast cancer cases diagnosed between 1988-1993 according to the SEER EOD classification scheme.

Objective 1 was completed in Year 03 of the project.

Objective 2 - Collect complete first course of treatment information for all breast cancers diagnosed from 1993 through 1997.

Until recently, most population-based registries outside the SEER Program have been incidence only registries and have not been concerned with the collection of treatment data. Since its inception, the CCR has collected information on the first course of cancer treatment as recorded in the medical record at the time it is abstracted. Unfortunately, the data are known to be incomplete, especially for those cancer sites such as breast cancer which may be treated with a first course of chemotherapy and eventually followed up with radiation therapy. Chemotherapy and radiation therapy are primarily given outside the acute care hospital setting, and hospital medical records often lack the details of the complete first course of therapy that was given.

Data on female breast cancers come to the CCR from multiple sources. Frequently a patient is treated at more than one hospital, and additional treatment information may be received from a physician's office. When a new patient record is received from a hospital by a regional registry, it is either entered as a new case or "consolidated" with the records from other facilities into a single record. Hospitals frequently abstract and report a case shortly after it is diagnosed and treated in that facility. Subsequently, the hospital registrar may learn of additional treatment and update the hospital record. The updated information is then transmitted to the regional registry as a "correction" record.

As stated in a prior progress report, due to limited resources the CCR had not developed software to process these correction records before initiating this project. Consequently there was an unknown amount of treatment information contained in the stockpiled correction records. This information needed to be processed and added to the main data base before any given breast cancer record could be compared with the standard recommended treatment, and before any routine follow-back to physicians concerning possible incomplete treatment could be initiated.

During Year 02 the CCR developed specifications for comparing correction record data with the main data base, and developed decision rules for handling discrepancies in order to automate as much of the process as possible. In Year 03 computer software for processing correction records was written, tested, and installed in the four different software systems used by the ten regional registries, and the backlog of breast cancer correction records was processed. (All of the specification and software development was funded with breast cancer tobacco tax funds that were available to the CCR.)

With correction record processing completed, we turned to examining CCR's breast cancer records for treatment completeness. As stated in the Year 01 Progress Report, standard/recommended/state-of-the-art treatment for each stage and type of breast cancer is included in the NCI's Physician Data Query (PDQ) system which is available to all practicing physicians via the Internet (http://cancernet.nci.nih.gov/clinpdq/soa/ Breast_cancer_Physician.html) or the NCI's Cancer Information Service (1-800-4-CANCER). Naturally, not all physicians utilize the PDQ, and some physicians do not feel that it is appropriate for NCI to "dictate" how patients should be treated, believing that the choice belongs to the physician and patient. Nevertheless, the comparison standard chosen for this project was the PDQ.

During Year 03 methods for comparing treatment information contained in the registry file with a treatment standard and, if different, conducting follow back to query physicians' offices were developed. The Breast Cancer Treatment Follow Back Protocol consists of: (1) a standard for comparing recommended breast cancer treatment with treatment recorded in the registry record; (2) computer programs to perform the comparison; (3) criteria for excluding cases from follow back; (4) updating physician addresses; (5) computer programs to generate customized letters to physicians requesting treatment on specific treatment that was recommended but not recorded in the registry record; (6) interaction with hospital cancer registry staff in order to determine who should perform the follow back, i.e. central registry or hospital registry staff; (7) criteria for intensity of follow back, i.e. multiple query letters and/or actual visits by program staff to physician offices to extract information from medical records; and (8) data entry onto "correction" records for processing to update registry data files. The Year 03 annual report presented the results of the first implementation of treatment follow-back by Region 8 for 1994 cases. Those results were presented this past year at the annual conference of the North American Association of Central Cancer Registries (NAACCR) (4) and the presentation materials are attached as Appendix I.

During the past year follow-back was completed for 1995 diagnosed cases in Region 8. Table 1 presents the results of that effort. A total of 2,058 requests were sent to physicians of record asking for additional treatment information. The response rate to these requests was 81% and additional treatment information was obtained for 33% of the follow-back cases.

As reported last year, during the course of implementing the Breast Cancer Treatment Follow Back Protocol for the CCR, we discovered the process was more time sensitive and resource intensive than we had imagined when we initially proposed this effort. Even with additional funds from the NCI and the California Breast Cancer Tobacco Tax Research Fund that are available to the CCR, we cannot perform follow back on all cases from 1993 through 1997. Cases diagnosed in 1993 and 1994 are now too old for their records to be readily available in physician offices. Follow back requires considerably more staff resources than we first estimated due to the necessity for multiple attempts to contact the physician of record, tracing physicians who have moved, interacting with hospitals for coordinating follow back activities that they may be engaged in, and physically going to physician offices to abstract treatment information from their files. Consequently, we modified our Scope of Work to collect first course of treatment information for all breast cancer cases statewide diagnosed only for the time period 1995 through 1996. That work is now in progress and is expected to be completed with a no-cost extension of this grant. Appendix II contains forms that will be used by the CCR Regional Registries to report the results of the treatment follow-back. Statewide results will be reported in the Final Report.

Objective 3 - Collect patient follow-up information on all breast cancers diagnosed from 1988 forward by linking the CCR files with Department of Motor Vehicles and voter registration files.

The results of our linkage with the Department of Motor Vehicles (DMV) files were described in the Year 02 annual report. A linkage of Region 1/8 cases was performed with the DMV this past year. We are in the process of developing the necessary software to update the results of this linkage as well as other linkages into the CCR database. We anticipate that a significant improvement in follow-up information will be realized as a result of this process.

Linkage with voter registration files has not been accomplished. This task would require more resources than are available, and it was deleted during budget negotiations at the beginning of the grant.

Objective 4 - Complete occupation/industry coding for all breast cancer cases from 1998 through 1997.

This objective was deleted during budget negotiations at the beginning of the grant.

Table 1. 1995 Treatment Follow-Back Report

Total Number of breast cancer cases for follow-back: 4545

Exclusionary codes:	Number
00 Complete Tx, no follow-back needed	1702
01 Non-resident	167
03 DC only	2
05 Physician only	25
07 Patient refused Tx	10
09 Hospital closed	4
10 No contact MD available	70
11 Patient expired	2
14 MD out-of-region	29
Total No. Excluded	2011 (44.2%)

Total number of cases mailed to physicians 2534

Total number of responses 2058 (81%)

Additional Tx obtained	684	(33%)
No additional Tx obtained	1374	(67%)

Objective 5 - Link CCR files with data from several large breast cancer screening programs to correlate screening status with subsequent diagnostic status.

In collaboration with the California Breast and Cervical Cancer Control Program (BCCCP) (funded by the Centers for Disease Control (CDC)), this past year the CCR linked a BCCCP file of 106,071 records of women who had been screened for breast and cervical cancer with a CCR file of all female cancer cases diagnosed between 1988 and 1997 that were available to the CCR as of January, 1998. The linkage yielded 2,397 cancers among the BCCCP clients, and 894 were breast cancers. The linked file was given to BCCCP for analysis, and the Battelle Corporation, under contract from the CDC, is using these linkage results in a evaluation study of the BCCCP. The final report of this study in currently in draft form (5) and is expected to be completed for release during 1999.

This past year the CCR, in collaboration with the California Breast Cancer Early Detection Program (BCEDP) (funded by the California Tobacco Tax Breast Cancer Fund), also linked a file of 144,476 records of BCEDP clients who had been screened for breast cancer with a CCR file of all female cancer cases diagnosed between 1988 and 1997 that were available to the CCR as of January, 1998. That linkage yielded 2,196 cancers among the BCEDP clients, and 969 of these were breast cancers. The linked file was given to BCEDP for analysis.

The CCR also collaborated in a study of breast cancer among California's Medi-Cal (the California Medicaid program) population. An earlier CCR report, *Breast Cancer in California* (6) showed that stage at diagnosis of breast cancer varied by SES in California, with lower SES being diagnosed at a later stage of diagnosis for all races. Following that report, we decided to investigate stage at diagnosis among women receiving Medi-Cal. Since mammograms and treatment are paid for by Medi-Cal, it was hypothesized that breast cancer stage at diagnosis would not be as high for the Medi-Cal population as it might be for uninsured and underinsured poor women. To examine this question, we performed a linkage with the CCR 1993 files and a file of Medi-Cal 1993 reimbursement claims. The Medi-Cal file consisted of 1,151,636 women over 30 who made some claim for payment in 1993. This was linked to 22,023 women resident in California who were diagnosed with breast cancer in 1993.

Figure 1 shows the percent of Medi-Cal breast cancer patients in five year age groups compared with non Medi-Cal breast cancer patients. Medi-Cal breast cancer patients are relatively older than the those not enrolled in Medi-Cal. Figure 2 shows the percent of Medi-Cal breast cancer cases by race/ethnicity. Overall, 11.1% of California's breast cancer cases in 1993 received Medi-Cal funded treatment. For non-white women, the percentages ranged from 20 to 26 percent. Figure 3 shows that Medi-Cal breast cancer patients were diagnosed at a later stage than non Medi-Cal breast cancer patients. After controlling for age and race, Medi-Cal breast cancer patients were still more likely to be diagnosed with late stage tumors when compared with those not enrolled in Medi-Cal [OR=1.77, 95% CI (1.62, 1.94)]. Figure 4 shows the percent of late stage diagnosis by race/ethnicity of the Medi-Cal patients compared to the those not on Medi-Cal. The percentage of Medi-Cal breast cancer patients diagnosed at a late stage is about 10 percentage points more than those not on Medi-Cal across all four race/ethnic groups examined.

Figure1. Percent MediCal Breast Cancer Patients Compared to Non MediCal by 5-Year Age Groups, 1993

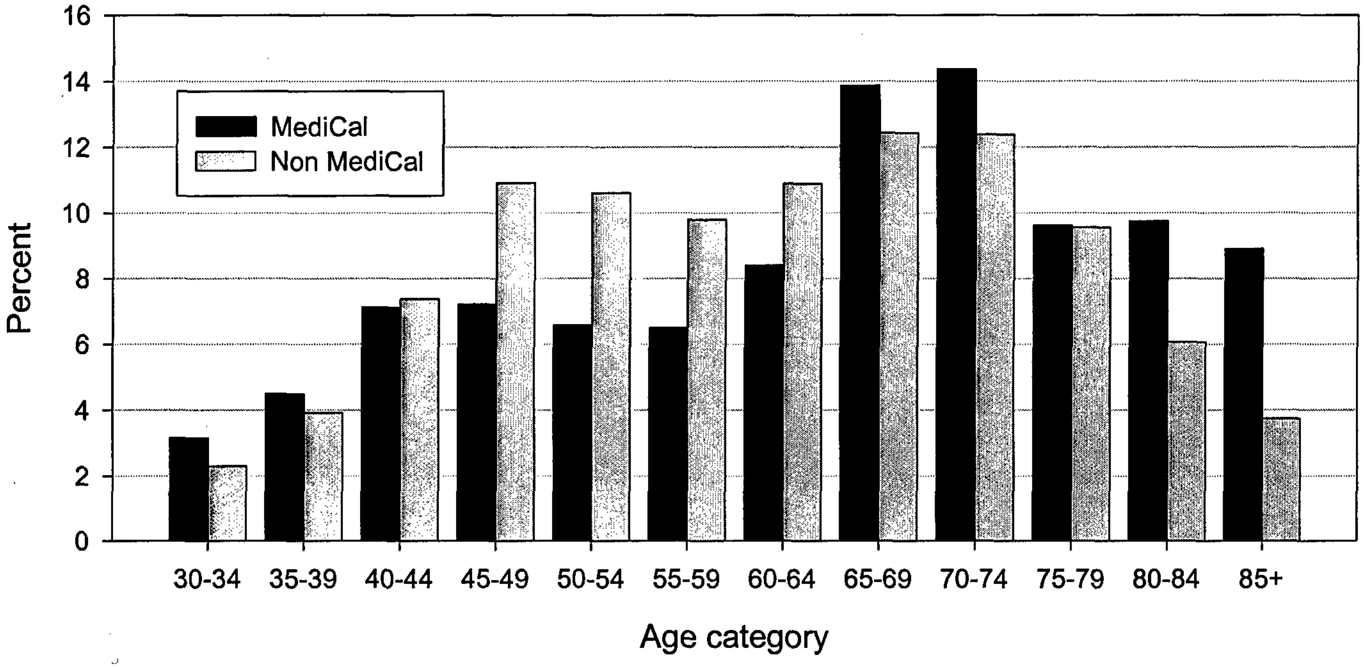


Figure 2. Percent MediCal Breast Cancer Cases by Race/Ethnicity, 1993

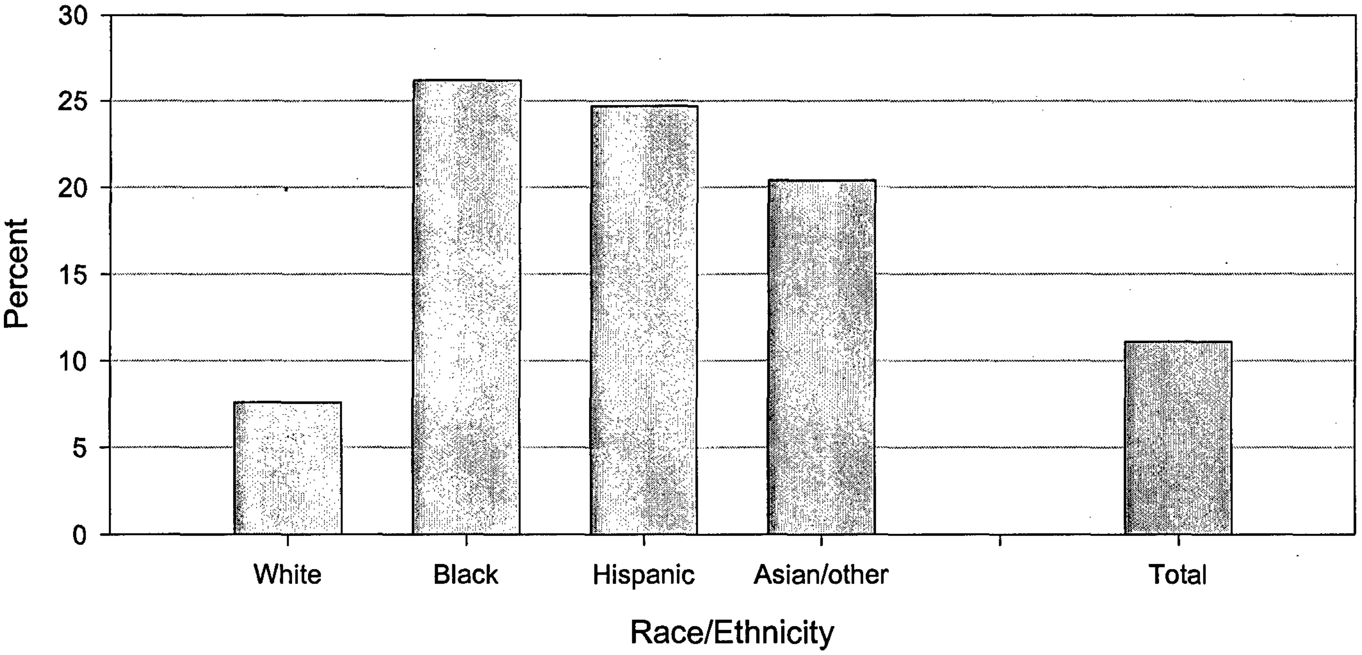


Figure3. Percent Stage at Diagnosis for MediCal Breast Cancer Patients Compared to Non MediCal, 1993

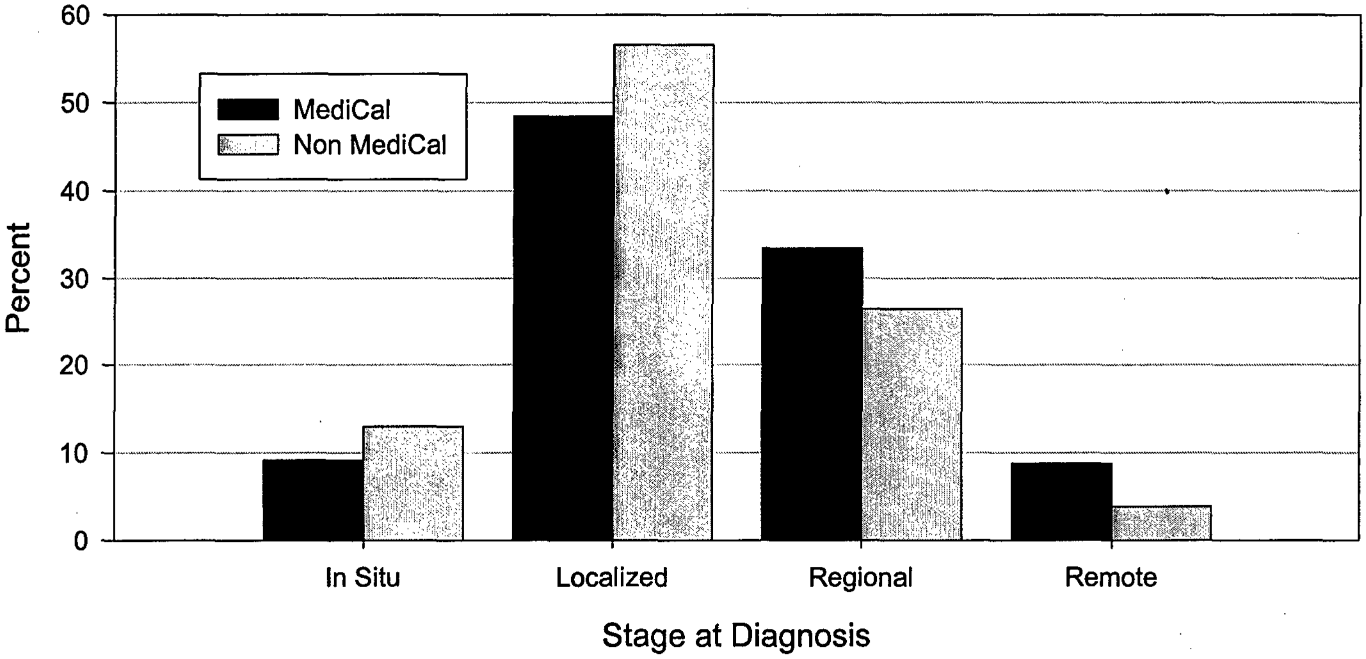
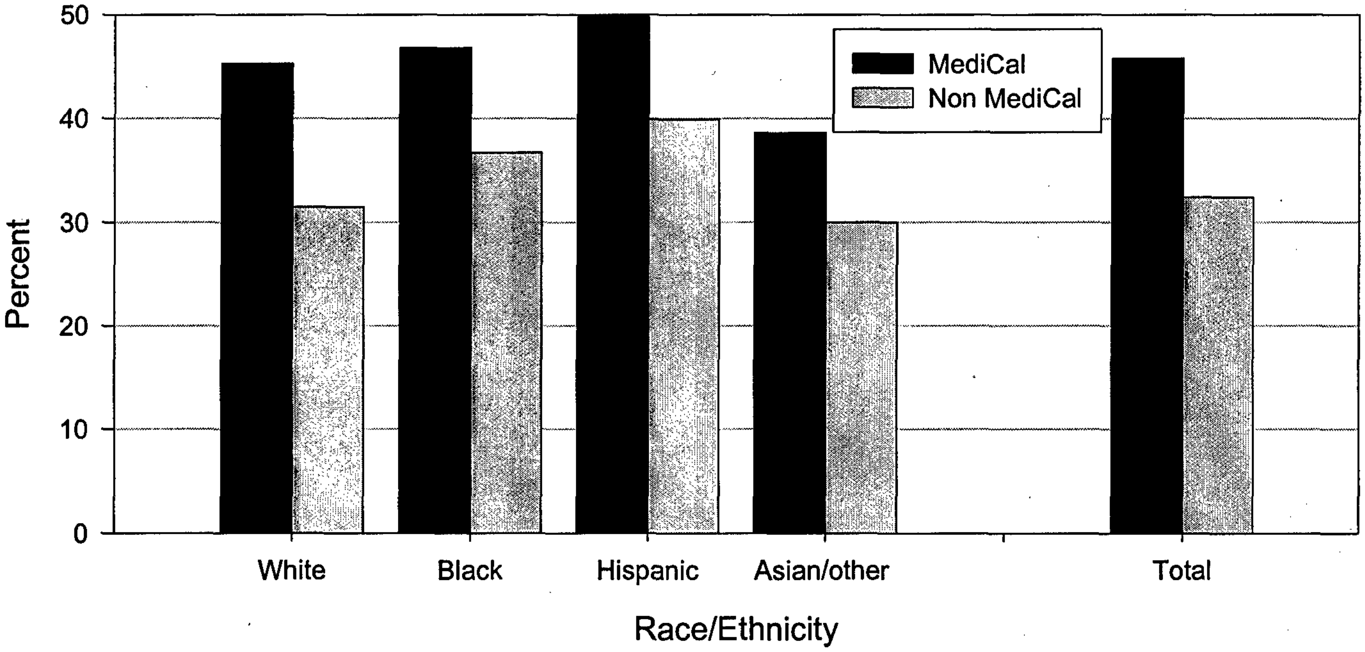


Figure 4. Percent Late Stage at Diagnosis for MediCal Breast Cancer Patients Compared to Non MediCal by Race/Ethnicity, 1993



After controlling for age, Medi-Cal breast cancer patients were still more likely to be diagnosed with late stage tumors than were patients not enrolled in Medi-Cal.

The results of these analyses have been presented at three conferences (7,8,9). Appendix III contains a draft of a manuscript, Breast Cancer Incidence in the California Medi-Cal Population (10), which is being prepared for publication.

Objective 6 - Link CCR files with hospital discharge and Medicare files to incorporate insurance status, expected hospital charges, and comorbidities into the CCR database.

Results of our linkages with the Health Care Financing Administration (HCFA) Medicare were described in our Year 01, Year 02 and Year 03 reports. Appendix IV contains our recently published paper on the utility of using Medicare files for population-based cancer registry case ascertainment (11).

The utility of hospital discharge data for follow-up purposes was described in our Year 02 report. A description of its usefulness for garnering insurance and comorbidity status follows. A total of 118,776 breast cancer cases diagnosed from 1988 through 1993 were linked with data from the California Office of Statewide Health Planning Data (OSHPD) for the years 1991 through 1994. 1991 was the first year that OSHPD data contained social security number, thus permitting linkages with CCR files. Breast cancer cases may not match with hospital discharge records for several reasons. The OSHPD database does not have names, only Social Security numbers, and the linkage fails when these numbers are missing or miscoded. In addition, breast cancers treated as outpatients do not appear in the hospital inpatient discharge database. Of the breast cancer cases recorded in the CCR, 69,261 (58.3%) matched at least one hospitalization record from OSHPD (Table 2). As expected, the linkage results were better for the years 1991 forward. The expected source of payment for the matched cases is presented in Table 3. Not suprisingly, the single largest insurer was the federal Medicare program. The average length of stay for these cases was 5.9 days, with an average cost per hospitalization of $12,358.

OSHPD linked cases reflect more serious breast cancer cases, i.e. those involving hospitalization. Table 4 shows that later stage tumors are more likely to be accompanied with hospitalization than early stage tumors. Table 5 confirms this and shows that cases treated b y mastectomy are more likely to match with hospital discharge data than are cases with breast-conserving surgery reflecting that more breast-conserving surgeries are performed on an outpatient basis than mastectomies.

The linkage with OSHPD data was useful for adding co-morbidity to the CCR database, although the differential in matching success by stage at diagnosis and treatment received will have to be considered be considered in the design of any research project utilizing these data. Table 6 presents the five most frequent principle diagnoses and first three comorbidities listed on hospital discharge abstracts. Of these hospitalizations, 32.8% had a code for breast cancer (invasive or in situ) as the principal diagnosis. Heart disease was frequently listed as a principal diagnosis (6.5%), first comorbidity (6.5%), second comorbidity (6.5%), and third comorbidity (9.2%). Diabetes was the next most frequently listed with 3.3% of the second and 3.2% of the third comorbidities.

Table 2. Number of breast cancers diagnosed in California by year of diagnosis matched to hospital records by year of discharge

Year of Diagnosis	N	Year of discharge 1991	1992	1993	1994	Total
1988	19,017	2,419	1,586	1,239	895	6,139 (32.3%)
1989	18,492	2,588	1,702	1,280	1,044	6,614 (35.8%)
1990	19,653	4,018	1,955	1,353	1,033	8,359 (42.5%)
1991	20,154	14,134	1,556	420	264	16,374 (81.2%)
1992	20,947	1,718	13,145	1,321	363	16,547 (79.0%)
1993	20,513	1,524	1,288	11,076	1,340	15,228 (74.2%)
Total	118,776	31,408	21,232	16,689	4,930	69,261 (58.3%)

Table 3. Expected source of payment for all hospitalizations matching breast cancers diagnosed in California from 1988 through 1993

Source of payment	Number of hospitalizations	%
Medicare	67,276	47.9
Medi-Cal	9,959	7.1
Worker's Compensation	179	0.1
Title V	2	0.0
Other Government	810	0.6
Blue Cross/Blue Shield	5,297	3.8
Insurance Company	18,648	13.3
HMO/PHP	34,188	24.3
Self-Pay	1,836	1.3
No Charge	204	0.1
Other Non-Government	444	0.3
Medically Indigent	1,598	1.1
Unknown	6	0.0
Total	140,447	100.0

Table 4. Number and percent of breast cancers diagnosed in California from 1991 through 1993, by AJCC stage at diagnosis and matching status to hospital discharge data

Stage	Matched (%)	Did not match (%)	Total
0	4,588 (59.0%)	3,184 (41.0%)	7,772
I	18,123 (79.3%)	4,733 (20.7%)	22,856
IIA	11,108 (84.7%)	2,000 (15.3%)	13,108
IIB	5,761 (88.2%)	774 (11.8%)	6,535
II, NOS	718 (86.0%)	117 (14.0%)	835
III	2,586 (87.8%)	358 (12.2%)	2,944
IV	1,867 (80.3%)	457 (19.7%)	2,324
Unknown	3,398 (64.8%)	1,842 (35.2%)	5,240
Total	48,149 (78.2%)	13,465 (21.8%)	61,614

Table 5. Percent of breast cancers diagnosed in California from 1991 through 1993 linked with hospital discharge data, by year of diagnosis and surgical treatment received.

Year of diagnosis	Breast-conserving surgery	Mastectomy
	% matched	% matched
1991	67.5%	88.2%
1992	64.5%	87.9%
1993	59.4%	84.9%
Total	63.5%	87.1%

Table 6. Five most frequently listed diagnoses and comorbidities (ICD-9 codes) for breast cancer cases diagnosed in California from 1991 through 1993

Principal Diagnosis	%	First comorbidity	%	Second Comorbidity	%	Third Comorbidity	%
Malignant neoplasm of female breast	30.6	Secondary malignant neoplasm of lymph nodes of axilla and upper limb	9.4	History of malignant neoplasm of breast	9.1	History of malignant neoplasm of breast	10.6
Maintenance Chemotherapy	4.0	Other forms of heart disease	6.5	Other forms of heart disease	6.5	Unspecified hypertensive disease	6.4
Other forms of heart disease	3.7	History of malignant neoplasm of breast	6.3	Unspecified hypertensive disease	6.2	Other forms of Heart disease	6.0
Ischemic heart disease	2.8	Secondary malignant neoplasm of bone and bone marrow	3.9	Diabetes mellitus	3.3	Ischemic heart disease	3.2
Carcinoma in situ of breast	2.3	Malignant neoplasm of female breast	3.8	Secondary malignant neoplasm of bone and bone marrow	3.2	Diabetes mellitus	3.2

The OSHPD linkage was successful. Use of the enhanced CCR database for research will require an understanding of its particularities and limitations.

Objective 7 - Design and produce a series of confidential and nonconfidential datasets with complete documentation and convenient access for researchers, and produce required reports for the USAMRDC.

Confidential and nonconfidential breast cancer datasets with SEER EOD coding are now available from the CCR to qualified researchers. Follow-up information from the linkages are also available. The Reference Section (below) lists the publications that have we have produced in the past year.

CONCLUSIONS

Work on this project is continuing. Follow-back to physicians for first course of treatment data has been more resource demanding that originally estimated, but the computer software problems have been resolved and follow-back activities are underway in all 10 regions of the state. We expect to complete all planned activities during the coming year with a no-cost extension of the grant.

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APPENDIX I

O'Connor L, Prehn, A, Topol B. Cancer treatment information collected from physicians' records. Presentation at the Annual Meeting of the North American Association of Central Cancer Registries. Vancouver, BC, April 22, 1998

NORTHERN
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CANCER TREATMENT INFORMATION COLLECTED FROM PHYSICIANS' RECORDS

LILIA O'CONNOR, MBA, CTR, ART
ANGELA PREHN, PH.D.
BARBARA TOPOL

- BACKGROUND
- STUDY QUESTIONS
- METHODOLOGY
- FINDINGS
- FUTURE PLANS

BACKGROUND

- Shift of cancer diagnosis and care to ambulatory setting
- Known missing treatment information in registry data
- Patterns of Care Studies

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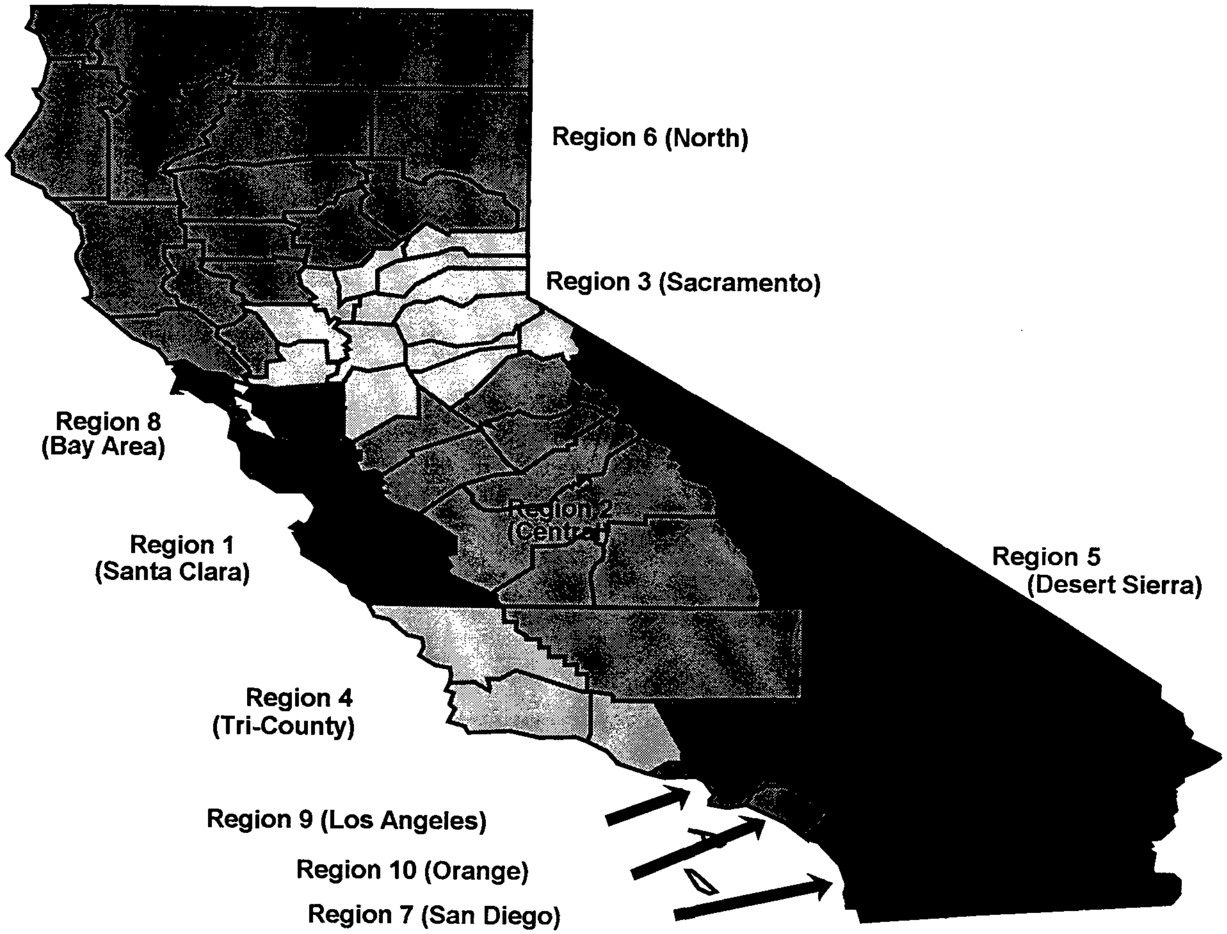
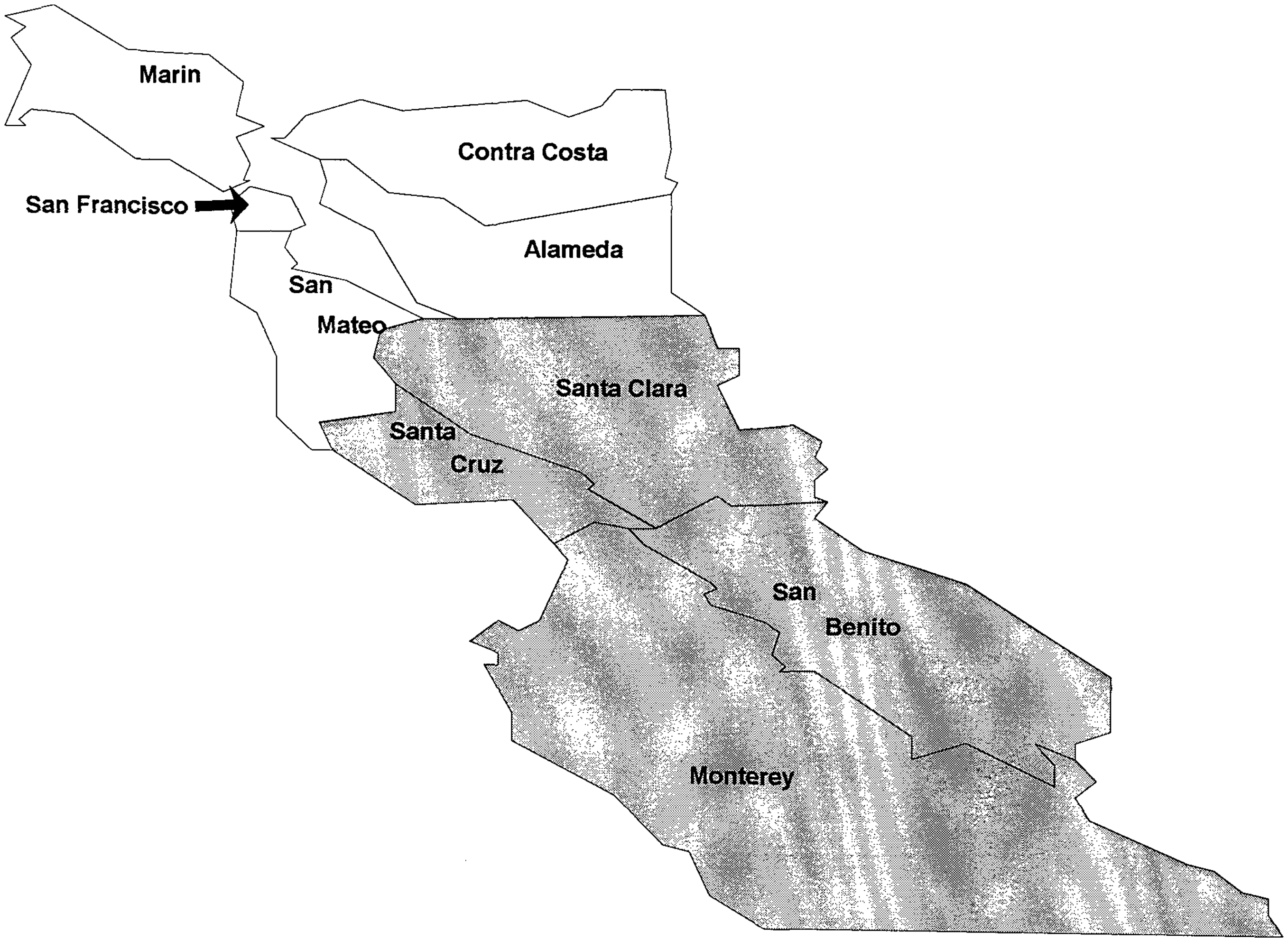


GREATER BAY AREA CANCER REGISTRY



GREATER BAY AREA CANCER REGISTRY

POPULATION	6 Million
ANNUAL ADMISSION RECORDS	42,000
ANNUAL INCIDENCE CASES	28,500
ANNUAL FOLLOW-UP CASELOAD	295,000

REPORTING SOURCES

ACOS HOSPITALS	28
NON-ACOS HOSPITALS	38
PATHOLOGY LABORATORIES	13
RADIATION THERAPY CENTERS	6
SURGERY CENTERS	24
HMO	12
* PHYSICIANS	230
TOTAL	351

* NCCC staff collects data at 156 physicians' offices

STUDY QUESTIONS

- How much additional information was collected from physicians' records?
- Did this differ by whether or not hospitals were ACOS-approved?

METHODOLOGY

- Criteria for selecting cases
- System
- Pitfalls

CRITERIA

- PHYSICIAN DATA QUERY (PDQ)
- NATIONAL COMPREHENSIVE CANCER NETWORK (NCCN)

PDQ RECOMMENDATIONS AND NCCN ONCOLOGY PRACTICE GUIDELINES:

- PDQ was developed by an expert panel
  (not exclusively breast cancer experts)
- NCCN was developed by physicians specializing in the diagnosis and treatment of breast cancer
- PDQ is updated more frequently than NCCN
- NCCN more detailed than PDQ
- NCCN is widely used

- NCCN developed treatment guidelines to provide quality of care cost effectively

- NCCN guidelines for breast cancer was distributed in 1996, thus, can be used only for 1997+ cases

- We will continue to use PDQ recommendations
- We are not evaluating the quality of car rendered by the physicians
- We want assurances that the treatment information we receive is complete

TUMORS IN STUDY

4,794 TUMORS IN DATABASE (1994 breast)
\- 1,091 EXCLUDED (INCOMPLETE DATA)
3,703 TUMORS STUDIED

OF THESE: 336 (9%) COMPLETE TREATMENT
596 (16%) ADD'L INFORMATION
2,771 (75%) NO ADD'L INFORMATION

ONLY LOOKED AT TUMORS TREATED AT ONE HOSPITAL

1994 BREAST CANCERS EXCLUDED

NON-RESIDENT
DC ONLY
FIRST DX AT AUTOPSY
PHYSICIAN ONLY CASES CORONER
SES
PATIENT REFUSED TX
HOSPITAL CLOSED
NO CONTACT MD AVAILABLE PATIENT
PIRED
DOCTOR OUT OF REGION

1994 BREAST CANCER

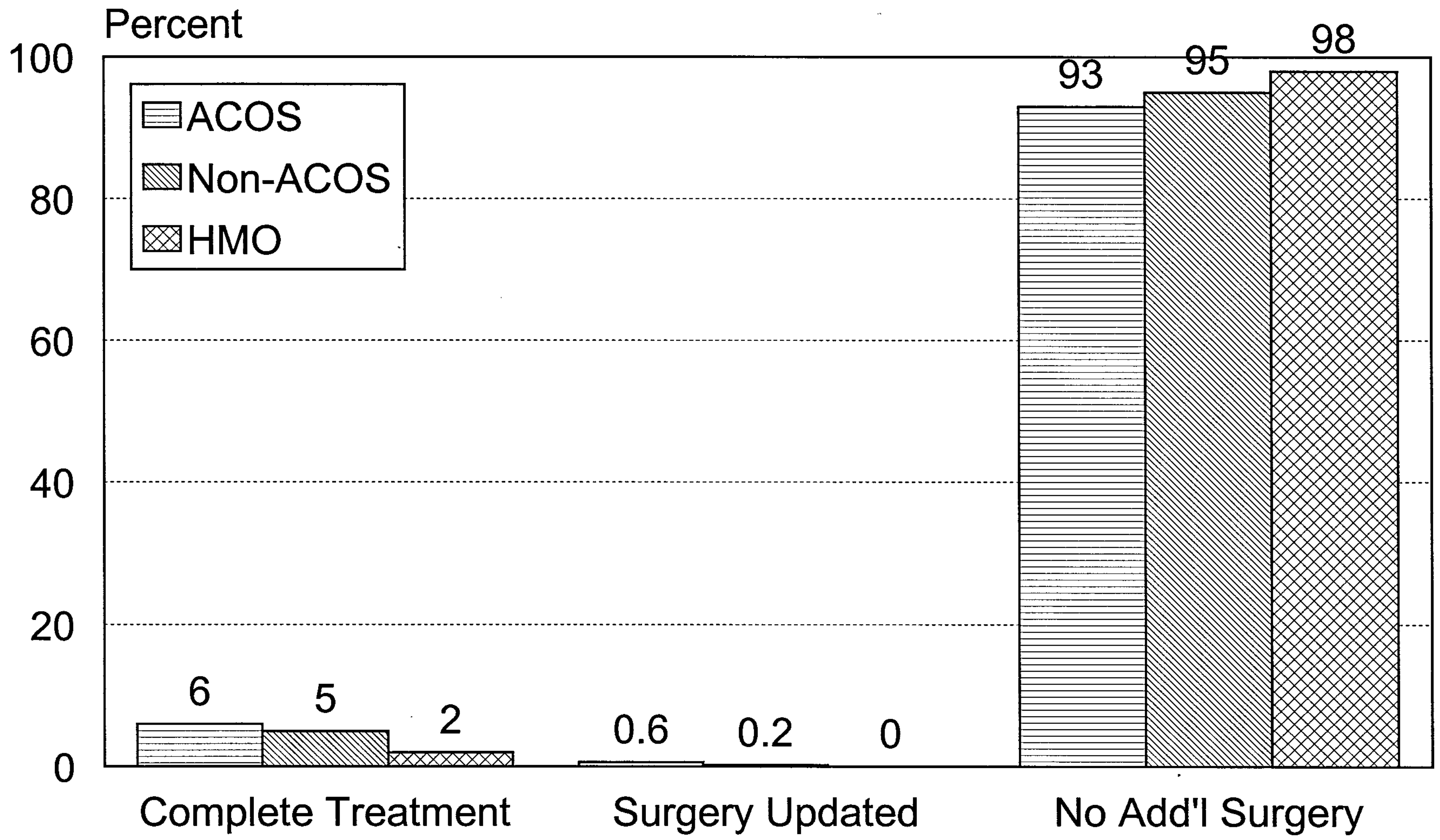
STUDIED 3703

QUERIED PHYSICIANS 2837

COMPLETION RATE (2302) 81 %

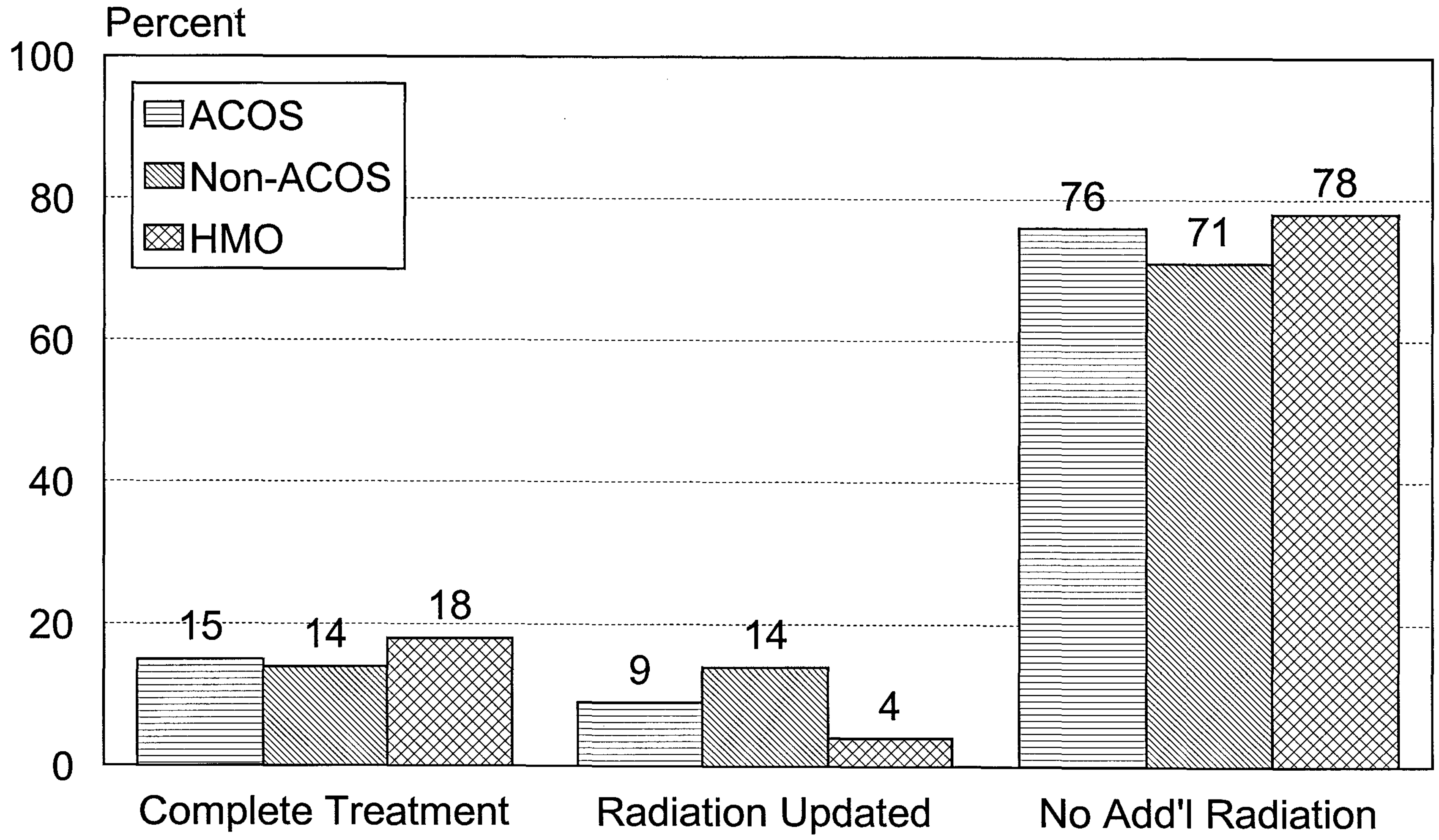
Surgery

by Hospital Status



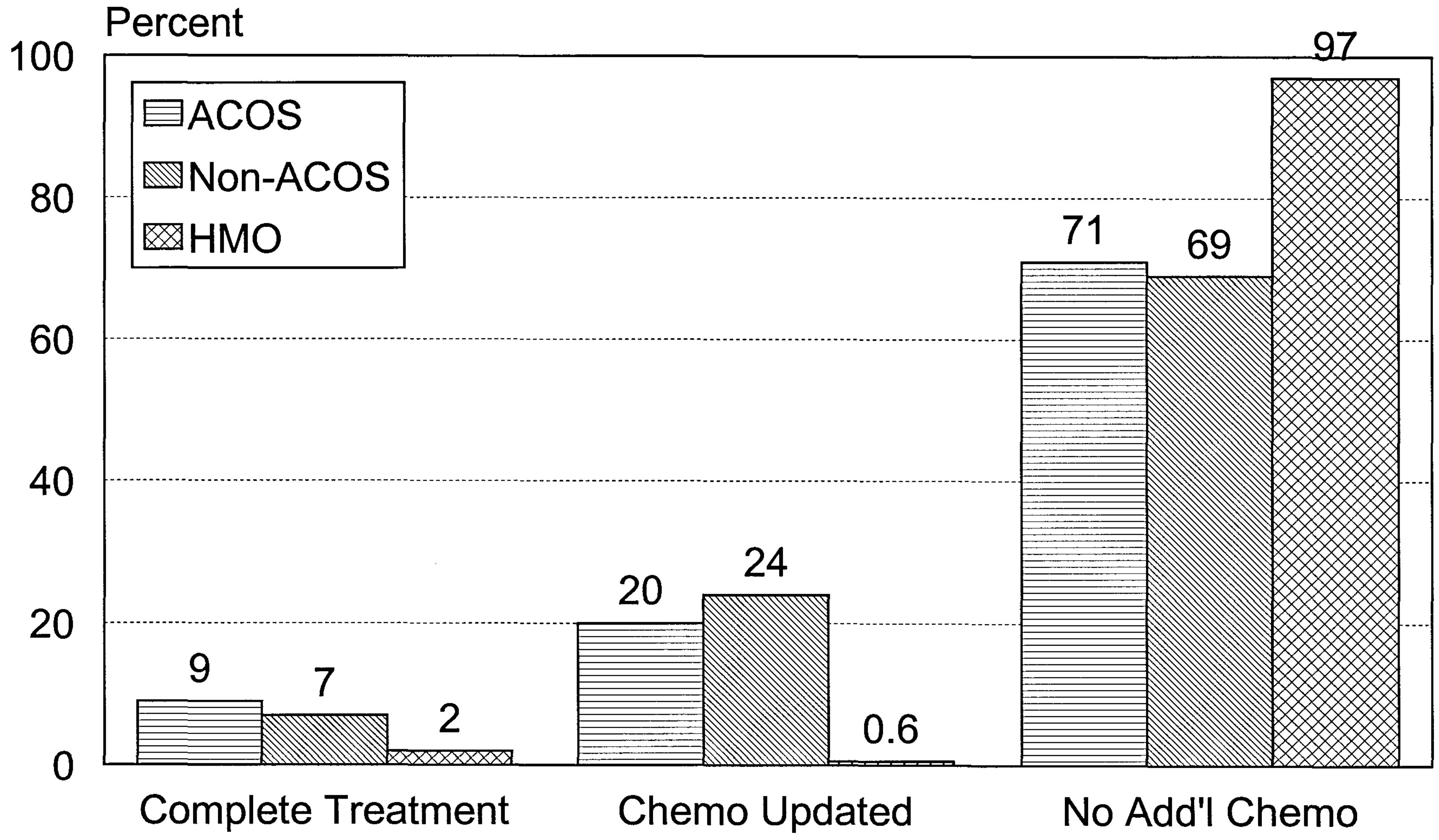
Radiation Treatment

by Hospital Status



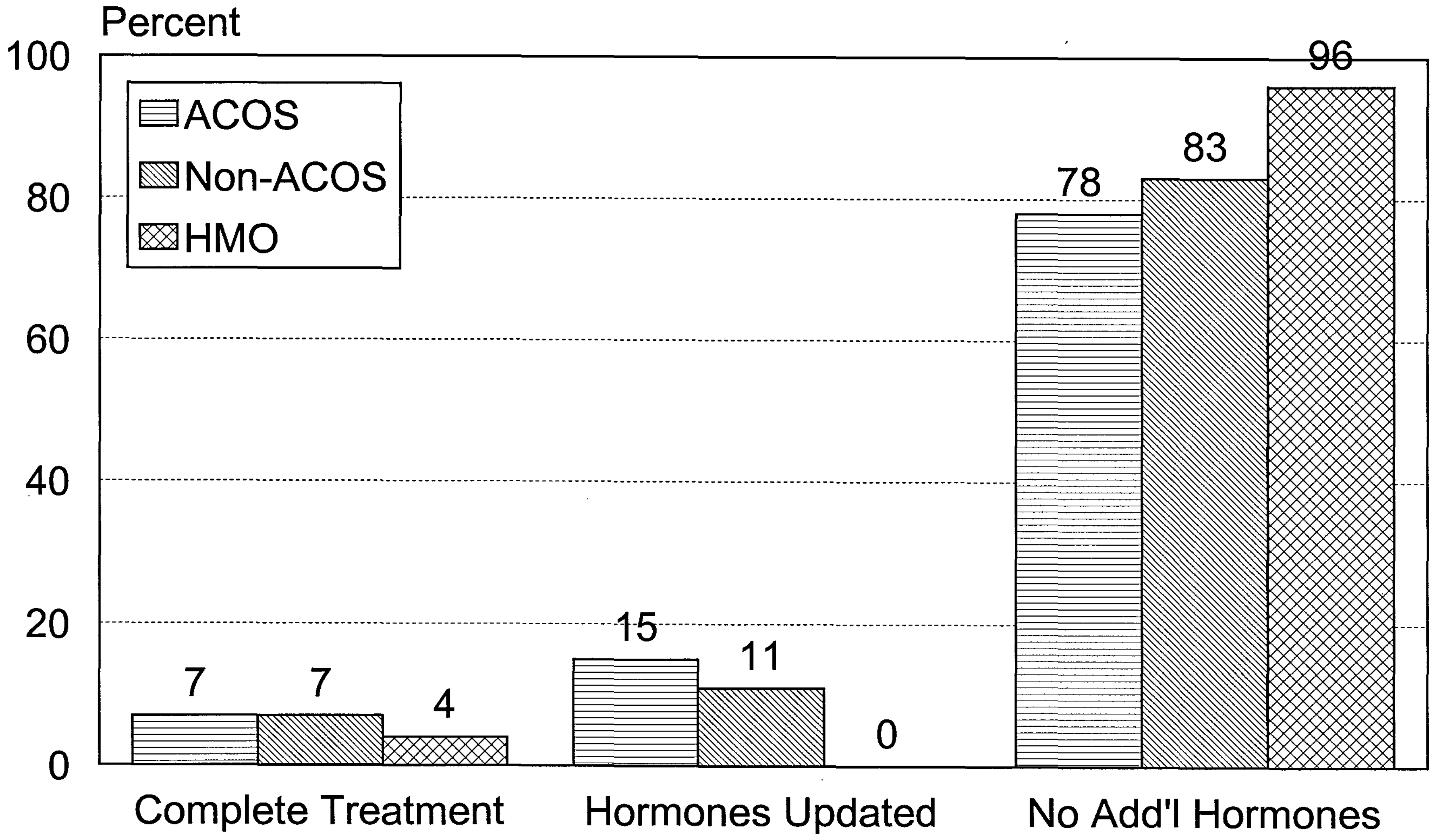
Chemotherapy

by Hospital Status



Hormone Therapy

by Hospital Status



PRELIMINARY RESULTS

1995 Breast cancers studied

4,545Tumors in Database

2,534Tumors queried for treatment

2,058 (81%) Completed

Of these: 684 (33%) additional information

1,374 (67%) no additional information

CONCLUSION

- We have missing treatment information in our registry.
- We need to continue to obtain this information from physicians.

FUTURE PLANS

- Do similar study on 1996 breast cancer
- Publish and disseminate information of findings to medical community
- Use registry's breast cancer treatment data for further studies
- Collect complete treatment information on other cancer sites

NORTHERN
CALIFORNIA
CANCER
CENTER

GREATER BAY AREA CANCER REGISTRY

We Register Quality And Excellence Is Our Goal

APPENDIX II

TREATMENT FOLLOW-BACK YIELD REPORTING FORMS

Number of Breast Cancer Cases Excluded From Treatment Follow-back By Reason and Diagnosis Year

	1995	1996
Number of Cases	____	____
TX Complete	____	____
<u>Reason for Exclusion:</u>		
Surgery not recommended	____	____
Other Tx not recommended	____	____
Non-Resident of Region	____	____
DC Only	____	____
First DX at Autopsy	____	____
MD Only Cases	____	____
Coroner Cases	____	____
Patient Refused TX	____	____
No Contact MD Available	____	____
Patient Expired	____	____
MD Out of Region	____	____
Hospital Out of Region	____	____
Military Hospital	____	____
Other (specify)	____	____
Total Number Excluded	____	____
Number for MD Follow-back	____	____

Follow-back Yield

	1995	1996
Number for MD Follow-back		
Number No Reply		
Number Refused to Reply		
Number of Responses		
% Responded		
Of Responses:		
Number, no add'l info		
%		
Number w/additional Tx info		
%		
Additional Tx Information:		
Number w/ Surgery		
Number w/ Radiation		
Number w/ Chemo		
Number w/ Hormonal		

Increase in Breast Cancer Treatment Information By Hospital Type

Year = 1995

	ACOS*	HMO	Oth.
% w/ Compete Tx:			
Before Fbk	____	____	____
After Fbk	____	____	____
Treatment Updated:			
% Surgery	____	____	____
% Radiation	____	____	____
% Chemo	____	____	____
% Hormone	____	____	____

Year = 1996

	ACOS*	HMO	Oth.
% w/ Compete Tx:			
Before Fbk	____	____	____
After Fbk	____	____	____
Treatment Updated:			
% Surgery	____	____	____
% Radiation	____	____	____
% Chemo	____	____	____
% Hormone	____	____	____

*ACOS=Received first course of Tx in an ACOS Hospital.

Follow-back Effort

	1995	1996
Number for MD Followback	____	____
Number 1st Mailing	____	____
Number of Responses	____	____
Number 2nd Mailing	____	____
Number of Responses	____	____
Number Mailings to 2nd MD	____	____
Number of Responses	____	____
Number of Phone Calls	____	____
Number of Cases from MD Office Visits	____	____
Amount of Staff Time: Number of hours/month x number months Or FTE/month x number of months	____	____

APPENDIX III

DRAFT

Perkins CI, Allen ME, Wright WE, Takahashi E, Stoodt G. Breast Cancer Incidence in the California MediCal Population. (Manuscript in preparation.)

DO NOT DISTRIBUTE

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*************************** DRAFT 08/31/98 *************************

Breast Cancer Incidence in the California Medi-Cal Population

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Breast Cancer Incidence in the California Medi-Cal Population

Executive Summary

Nearly one million women 30 to 64 years old in California receive health care through Medi-Cal. Because Medi-Cal covers the cost of mammograms and clinical breast examinations when ordered by a health care provider, these women are not eligible to receive free breast cancer screening through state- and federally-funded programs. However, very little information has been available about the breast cancer experience of this group of women to indicate whether intervention programs directly targeted to them and their providers are needed.

By linking Medi-Cal eligibility files with cancer cases on the California Cancer Registry, the Medi-Cal status of all women diagnosed with breast cancer in 1993 was ascertained. This unique linkage demonstrates that Medi-Cal is responsible for the health care of a substantial proportion of women diagnosed with breast cancer. Overall, one of every twelve breast cancers among women 30 to 64 years old were diagnosed in women covered by Medi-Cal; among black and Hispanic women, who have a higher proportion of women covered by Medi-Cal, nearly one of five breast cancers were diagnosed in women on Medi-Cal. Given the large proportion of breast cancer cases receiving care through Medi-Cal, efforts to reduce breast cancer mortality in California must address the needs of these women and the system through which they receive care.

Furthermore, this study shows that women on Medi-Cal who develop breast cancer are significantly more likely to be diagnosed with late-stage disease than other women with breast cancer. This finding, which was true regardless of age, race/ethnicity, or length of time covered by Medi-Cal, indicates that women on Medi-Cal are not being adequately screened for breast cancer, or are not receiving timely follow-up after screening.

This study clearly demonstrates the need for improved breast cancer screening in the Medi-Cal population. Strategies must be developed and additional resources allocated to improve access to and utilization of breast cancer screening and follow-up services in this underserved population.

Breast Cancer Incidence in the California Medi-Cal Population

Introduction

One of the strongest predictors of breast cancer survival is the extent of disease at diagnosis, or the degree to which the cancer has spread when first discovered. The five-year relative survival rate is 97.4 percent for invasive cancers confined to the breast at diagnosis, but decreases to 76.7 percent for cancers that have spread to lymph nodes or adjacent tissues when diagnosed, and decreases even further to 21.9 percent for tumors that have already spread to other parts of the body when first discovered (1). Clinical trials have demonstrated that screening reduces late-stage disease and can reduce breast cancer mortality by up to thirty percent. The last decade has witnessed a highly successful public health effort to increase the number of women who receive routine breast cancer screening. The proportion of women age 40 and older in California who self-reported having a mammogram in the previous two years increased from 38 percent in 1987 to 73 percent in 1997 (2). Concomitantly, breast cancer incidence rates showed a significant shift to earlier stage diagnoses and the breast cancer mortality rate declined (3).

State- and federally-funded programs have provided free mammograms and clinical breast exams to uninsured low income women in California since 1992 (4). Because Medi-Cal pays for mammograms and clinical breast exams when ordered by a health care provider, Medi-Cal women are not eligible for screening through these programs. Limited information is available to evaluate whether women who receive health care services through Medi-Cal are being adequately screened for breast cancer and to quantify their overall risk of developing breast cancer. To better characterize the breast cancer experience of these women, the statewide, population-based California Cancer Registry was linked with 1993 Medi-Cal eligibility files to determine the Medi-Cal status of all women 30 to 64 years old who were diagnosed with breast cancer in 1993.

Three key questions were addressed:

1. What proportion of women with breast cancer in California receive health care through Medi-Cal? The larger this proportion is, the more critical it becomes to take this health care system into consideration when developing strategies to reduce breast cancer mortality.

2. What proportion of Medi-Cal women with breast cancer are diagnosed with late-stage disease, and how does this compare to other women with breast cancer? If Medi-Cal women with

breast cancer have a higher proportion of late-stage tumors than other women, this may indicate that they are not being adequately screened for breast cancer.

3. Are women who receive health care through Medi-Cal at higher or lower risk of developing breast cancer than other women in California? Question 2 above examines the likelihood of having late-stage disease given that a breast cancer has been diagnosed, but it does not address the likelihood, or risk, of developing breast cancer to begin with. This question examines the overall risk of developing breast cancer among women who receive health care through Medi-Cal.

Methods

Medi-Cal eligibility

1993 Medi-Cal eligibility files for all women age 30 and over were obtained from the California Department of Health Services Medical Care Statistics Section (MCSS). A woman was included on the eligibility files if she was covered by Medi-Cal in 1993, whether or not a claim was submitted for medical services provided to her. Information was not available on women who would have met the eligibility criteria for Medi-Cal, but did not apply.

The eligibility files provided by MCSS listed a woman once for each month during which she was covered by Medi-Cal, with information on Medicare coverage during the same month. Personal identifiers on the file included first and last name, date of birth, social security number, and zip code of residence. The files provided by MCSS contained approximately 14 million records. Multiple records for the same woman (for multiple months of eligibility) were initially identified by social security number. Because a woman could be listed with more than one social security number, the file which had been unduplicated based on social security number was further unduplicated by linking the file with itself using the probablistic linkage program Automatch (5), using name, date of birth, and zip code of residence. When a temporary social security number had been assigned to a woman by Medi-Cal (last digit was a character) and another record was present for the same woman with a valid social security number, the valid number was retained. Medi-Cal and Medicare eligibility status were consolidated for a woman in the unduplication process.

The unduplicated file contained 1,415,303 women age 30 and over who were covered by Medi-Cal during at least one month in 1993. Information was retained on month-by-month Medi-Cal and Medicare coverage. Because the vast majority of women age 65 and older on Medi-Cal were also covered by Medicare, this study was restricted to women age 30 to 64 years old. Among the 904,201 women covered by Medi-Cal in this age group, 74,512 (8.2%) were covered by Medicare during each month they were covered by Medi-Cal, and another 11,739 (1.3%) were eligible for Medicare at some point during the year. Because Medicare coverage of breast cancer screening is different from that of Medi-Cal, women with any Medicare coverage were also excluded from the study.

This study therefore included the 817,950 women aged 30 to 64 years old who were covered by

Medi-Cal during at least one month in 1993 and were not covered by Medicare at any time during the year. These women accounted for 12 percent of the California female population in this age group. Race/ethnicity was not specified on the Medi-Cal eligibility file for 72,367 (8.8%) of these women.

Not all women who would qualify for Medi-Cal apply for benefits. Although the majority of persons receive Medi-Cal as part of public assistance benefits package through such programs as Aid to Families with Dependent Children or Supplemental Security Income, persons who do not meet the income criteria for cash grants may still qualify for Medi-Cal on a share of cost basis. These Medi-Cal recipients are required to pay a fixed dollar amount for health-care services each month before Medi-Cal coverage begins. Among persons who would potentially qualify for share of cost Medi-Cal, women who have or anticipate health-care costs to diagnose or treat a breast problem may be more likely to apply for Medi-Cal than women with no health concerns.

This potential selection of "at risk" women into the group of women covered by Medi-Cal out of the potentially eligible pool of unknown size may bias results. The proportion of late-stage disease among women with breast cancer on Medi-Cal will be biased upwards if women with late-stage disease are more likely than women with early-stage disease to apply for and/or qualify for Medi-Cal benefits. Similarly, incidence rates will be biased upwards if women with breast cancer are more likely than women without breast cancer to apply for and/or qualify for Medi-Cal benefits.

The Medi-Cal eligibility files obtained from MCSS did not identify share of cost recipients or provide information on the basis for Medi-Cal eligibility. To evaluate and control for the potential biases discussed above, women on Medi-Cal were divided into two groups: those who had Medi-Cal benefits for the entire 1993 calendar year, and those who did not. Since all diagnoses occurred during 1993, it is much less likely that women on Medi-Cal for the entire year obtained Medi-Cal benefits for reasons related to breast cancer. Data for these women should therefore more accurately reflect the cancer experience of the "Medi-Cal population."

Breast cancer case ascertainment

A list of all women diagnosed with *in situ* or invasive breast cancer during 1993 was obtained from the California Cancer Registry (CCR). CCR is a statewide, population-based cancer registry which has been mandated by law since 1985; statewide reporting was fully implemented in 1988. Case reporting is estimated to be virtually complete for 1993. CCR contains personal identifiers, including first and last name, date of birth, and social security number, as well as detailed information on tumor characteristics, date of diagnosis, and extent of disease at diagnosis. Neither source of payment for medical services or health care coverage was collected by CCR in 1993.

Linkage

The Medi-Cal status of all breast cancer cases was determined by linking the unduplicated Medi-Cal eligibility file with cases of female breast cancer on CCR, using Automatch (5). First name, last name, date of birth, social security number, and zip code of residence were used in the linkage process. Of breast cancer cases matched to women on the Medi-Cal eligibility file, 45 percent were an exact match on all fields and 22 percent were exact matches on name, date of birth, and social security number, but not zip code. The remaining 33 percent of matches were not exact on one or more fields, but had a high enough probability score to be considered matches or were visually reviewed and considered matches. Altogether, 92 percent of matches were exact on date of birth, 87 percent were exact on social security number, and 85 percent were exact on first and last name.

Stage at diagnosis

Information on stage at diagnosis was obtained from CCR. Early-stage tumors were defined as *in situ* (a tumor that is malignant, but has not yet extended through the first layer of cells surrounding the duct in which it is growing) and invasive tumors that were confined to the breast when diagnosed. Late-stage breast cancers were defined as those which had already spread beyond the breast itself to lymph nodes, adjacent tissues, or other organs, at diagnosis. Race/ethnic differences in stage at diagnosis were evaluated using the race/ethnic information on CCR from the medical record, which was more completely reported than on the Medi-Cal eligibility file. Among female breast cancers in this age group, 1.3 percent were of unknown race/ethnicity on CCR.

The proportion of late-stage disease was calculated for women not on Medi-Cal during 1993, for all women on Medi-Cal, and for women on Medi-Cal during the entire year and for less than 12 months. Age- and/or race-adjusted prevalence ratios for late-stage breast cancer were calculated with the Cochran-Mantel-Haenszel method (6) using SAS (7).

Cancer incidence rates

Because of the likelihood that at least some women with Medi-Cal coverage for only part of the year applied or qualified for Medi-Cal because of breast-related problems, incidence rates were only calculated for women who received health care services through Medi-Cal for the entire year. Race-specific incidence rates in the Medi-Cal population were calculated using race/ethnic information on the Medi-Cal eligibility file so that the numerators and denominators would be internally consistent. Five race/ethnic categories were used: non-Hispanic white (170,949 Medi-Cal women), Hispanic (117,748 Medi-Cal women), black (86,609 Medi-Cal women), Asian/Other (48,134 Medi-Cal women), and unknown (57,921 Medi-Cal women). Denominators for incidence rates in the Medi-Cal population were the number of women on the unduplicated Medi-Cal file who were eligible for the entire twelve-month period by five-year age category and race/ethnicity. Numerators were based on cancer cases diagnosed in these women in 1993 based on the linkage between CCR and the Medi-Cal eligibility file.

Breast cancer incidence rates (the number of new cases diagnosed in 1993 per 100,000 women) were calculated for all breast cancers combined, including *in situ* tumors, and for late-stage disease only. Incidence rates were calculated by five-year age category and race/ethnicity, and were age-adjusted by the direct method (8) to the 1993 California female population, 30 to 64 years old (9).

To calculate comparable incidence rates among women not covered by Medi-Cal, the number of women on Medi-Cal in a given age group must be subtracted from the total number of women in California in that age group. Although this could be done for all races combined, the number of women not covered by Medi-Cal in each race/ethnic group could not be accurately calculated because of the large number of Medi-Cal women for whom race/ethnicity was not specified on the Medi-Cal eligibility files. Therefore, cancer incidence rates in the Medi-Cal population were compared to rates in the state as a whole. Since statewide rates include women on Medi-Cal, this method underestimates differences between the Medi-Cal and non-Medi-Cal women, especially among black and Hispanic women. Differences between Medi-Cal and statewide rates should be interpreted with caution, and tests of statistical significance were not performed. Statewide rates were based on cases reported to CCR as of April 1996 and on population estimates from the California Department of Finance (9).

Results

Of the 10,746 *in situ* and invasive breast cancers diagnosed in 1993 among California women age 30 to 64 years old, 867 (8.1%) were diagnosed in women who were covered by Medi-Cal at some time during the year, and were not on Medicare (Table 1). Of the 3,616 late-stage tumors diagnosed statewide in this age group, 443 (12.3%) were diagnosed in Medi-Cal women (Table 1). Among black and Hispanic women, who have a higher proportion of women covered by Medi-Cal, nearly 20 percent of breast cancers and 25 percent of late-stage breast cancers among women in this age group were diagnosed in women on Medi-Cal (Table 1, Figure 1).

Diagnosis in relation to Medi-Cal eligibility

Of the 867 breast cancers diagnosed among women who had Medi-Cal coverage during at least one month in 1993, 714 (82.4%) were diagnosed while the woman was covered by Medi-Cal (Table 2). The other cancers were diagnosed either before Medi-Cal coverage began or after Medi-Cal coverage had been discontinued. Of the 714 women diagnosed during a month that they had Medi-Cal benefits, 137 were diagnosed during the first month of Medi-Cal coverage. Of the 153 breast cancers diagnosed when the woman was not covered by Medi-Cal, the majority (135) were diagnosed before Medi-Cal coverage began. For a small number of these women (23 cases, 2.7 percent of all Medi-Cal cases), the breast cancer was diagnosed six or more months before Medi-Cal coverage began.

The relationship between diagnosis and Medi-Cal eligibility indicates that it is possible that some women applied for Medi-Cal specifically because of a breast-related problem or qualified for Medi-Cal because of poverty or disability associated with breast cancer treatment and illness. This has the greatest likelihood of being true among women who were diagnosed prior to Medi-Cal coverage, or who were diagnosed during the first month of coverage. On the other hand, women who were covered by Medi-Cal for the entire 12 month period were probably the least likely to have obtained Medi-Cal coverage for a breast-related problem, and may therefore reflect the least biased estimates of breast cancer risk. Women covered by Medi-Cal for the entire year were therefore analyzed separately from those who were not on Medi-Cal for the entire year. Of the 817,950 women in this age group covered by Medi-Cal in 1993, 481,091 (58.8%) received Medi-Cal for the entire year. Women who were on Medi-Cal for less than a year were covered for an average of six months.

Breast cancer stage at diagnosis

More than half (51.1%) of the breast cancers among women covered by Medi-Cal were diagnosed at late stage, compared to a third (32.1%) of those diagnosed among California women not on Medi-Cal. The proportion of late-stage tumors was higher among women on Medi-Cal for less than a year (58.1%) than among women on Medi-Cal for the entire year (44.1%) (Table 3).

The proportion of late-stage tumors was higher among Medi-Cal than non-Medi-Cal women in all age groups. Women on Medi-Cal for less than 12 months had the highest proportion of late-stage tumors, regardless of age (Table 3, Figure 2). However, women who were covered by Medi-Cal for the entire year were still more likely than non-Medi-Cal women to be diagnosed at late stage, regardless of age (Table 3). The difference was more pronounced among women age 40 and older, for whom routine breast cancer screening is recommended by national organizations. Although women age 30 to 39 were somewhat more likely to have been diagnosed with late-stage disease if they were on Medi-Cal for the entire year than non-Medi-Cal women, the difference was not statistically significant (prevalence ratio 1.1, 95% confidence interval 0.9 - 1.4, controlling for age and race/ethnicity).

The proportion of late-stage tumors was higher among Medi-Cal than non-Medi-Cal women in all four race/ethnic groups. However, the relationship between stage at diagnosis and duration of Medi-Cal coverage varied by race/ethnicity (Table 4, Figure 3). Among black and non-Hispanic white women, women on Medi-Cal for only part of the year had the highest proportion of late-stage tumors, and women on Medi-Cal for the entire year had a proportion of late-stage tumors which was intermediate between non-Medi-Cal women and women with less than a full year of coverage. Among Hispanic women, non-Medi-Cal women and women on Medi-Cal for the entire year had a similar proportion of late-stage tumors, but those on Medi-Cal for only part of the year had a much higher proportion. Among Asian/Other women, the highest proportion of late-stage tumors was among women on Medi-Cal for the entire year.

These differences may result from random variation due to small numbers or may reflect race-specific differences in factors associated with applying for and obtaining Medi-Cal coverage. Only 43 percent of Hispanic women on Medi-Cal were covered for the entire year, compared to 67 percent of non-Hispanic women.

Limiting the analyses to women who had Medi-Cal benefits during the entire calendar year in which they were diagnosed, and who therefore may represent the least biased information, women on

Medi-Cal with breast cancer were 30 percent more likely to have late-stage breast tumors than women not on Medi-Cal diagnosed with breast cancer. Controlling for race/ethnicity and age and excluding cases of unknown race/ethnicity, the difference was statistically significant (prevalence ratio 1.3, 95% confidence interval 1.1 - 1.4) (Table 5). Controlling for age, the difference was evident and statistically significant in each race/ethnic group except among Hispanic women (Table 5).

Incidence rates

The age-adjusted breast cancer incidence rate in 1993 among women 30 to 64 years old on Medi-Cal for the entire year was 113.9 new cases per 100,000 women, which was approximately 25 percent lower than the comparable statewide rate of 156.0 (Table 6). However, the age-adjusted incidence rate for late-stage breast cancer in Medi-Cal women was nearly the same as women statewide (49.9 and 52.5 per 100,000, respectively) (Table 6).

The difference between breast cancer incidence rates in Medi-Cal women and women statewide increased with age; rates were 15 percent lower among 30-34 year old women on Medi-Cal, and increased to 35 percent lower among women 60-64 years old. The late-stage incidence rate was approximately the same in Medi-Cal women as women statewide in all age categories (Table 6, Figures 4 and 5).

The overall breast cancer incidence rate was lower among Medi-Cal women than among women statewide regardless of race/ethnicity (Table 7, Figure 6). The difference was largest among Asian/Other and Hispanic women, for whom rates were 30 percent lower among Medi-Cal women. The difference was smallest among black women, for whom rates were 10 percent lower among Medi-Cal women than women statewide. However, since women on Medi-Cal comprise a relatively large proportion of black and Hispanic women and they are included in the statewide rates, the difference in rates between black and Hispanic women on Medi-Cal and not on Medi-Cal is underestimated. In contract, the late-stage breast cancer rate among Medi-Cal women was very similar to women statewide regardless of race/ethnicity (Table 6, Figure 7).

About 12 percent of women on Medi-Cal for the entire year were of unknown race/ethnicity. The incidence rate among these women was higher than the rate for Asian/Other and Hispanic women, and lower than the rate for black and non-Hispanic white women, indicating that this group probably contains women from a mixture of race/ethnic groups (Table 7). The exclusion of these women from the race group to which they belong has an unknown effect on the race-specific rates for women on Medi-Cal. Of the cancers diagnosed among Medi-Cal women who had unknown race on the Medi-Cal eligibility file, 40 percent were classified as non-Hispanic white on CCR, 33 percent as Hispanic, 17 percent as Asian/Other, and 8 percent as black.

Discussion

This unique linkage of Medi-Cal eligibility files and CCR demonstrates that a substantial proportion of women under the age of 65 with breast cancer in California receive health care through Medi-Cal. In 1993, one of every twelve breast cancers and one of eight late-stage breast cancers among women 30 to 64 years old were diagnosed in women who were covered by Medi-Cal during the year. Among black and Hispanic women, who have a higher proportion of women covered by Medi-Cal, nearly one of five breast cancers and one of four late-stage breast cancers among women in this age group were diagnosed in women covered by Medi-Cal. Public health interventions designed to reduce breast cancer mortality through improved screening and treatment must address the needs of this underserved population and the system through which they receive care.

Among women with breast cancer, Medi-Cal beneficiaries were more likely to be diagnosed with late-stage disease than other women, regardless of race/ethnicity or age. One possible explanation for this finding is that women with late-stage disease were more likely than those with early-stage disease to qualify for Medi-Cal due to cancer-related disability or poverty. Because this study examined diagnosis and eligibility within the same calendar year and the majority of women (85%) were covered by Medi-Cal when diagnosed or prior to diagnosis, this is unlikely to completely account for the finding. In addition, extent of disease on CCR is based on information at diagnosis, and does not reflect progression of the disease over time.

Another possible explanation for a higher proportion of late-stage disease among women covered by Medi-Cal is that women with breast problems or cancer are more likely to apply for Medi-Cal, especially on a share of cost basis. When women on Medi-Cal for less than the entire calendar year were excluded from the analysis, the proportion of late-stage tumors among women on Medi-Cal declined from 51.1 percent to 44.1 percent. However, this was still significantly higher than the proportion of late-stage tumors among women with breast cancer who were not on Medi-Cal during 1993 (32.1%). The proportion of late-stage tumors was significantly higher among women on Medi-Cal for the entire year than among non-Medi-Cal women in all race/ethnic groups except Hispanic women.

Women diagnosed with breast cancer who were on Medi-Cal for the entire year had a higher proportion of late-stage disease than non-Medi-Cal women in each age group. However, the differences were more pronounced among women age 40 and older, when routine breast cancer screening is recommended. The fact that younger women on Medi-Cal had a higher, but not statistically significant, proportion of late-stage disease may indicate that some of the excess in late-stage disease is related to factors other than screening.

Women on Medi-Cal for part of the year who were diagnosed with breast cancer during 1993 had the highest proportion of late-stage disease (58.1%). As discussed above, this may, in part, reflect selection bias. However, it is likely that other factors are involved as well. Many of these women may have been uninsured prior to qualifying for Medi-Cal, and so had limited access to cancer screening services. Medical services and diagnosis may have been delayed until the cancer was too advanced to ignore or until Medi-Cal coverage could be obtained.

Overall breast cancer incidence rates in 1993 were about 25 percent lower among women covered by Medi-Cal for the entire year than among women statewide. It is likely that the difference would have been greater if it had been possible to exclude women on Medi-Cal from the statewide rates. This lower risk reflects, in part, the fact that a higher proportion of women covered by Medi-Cal are Hispanic and black than in the population as a whole, and these race/ethnic groups have breast cancer incidence rates which are 40 percent and 10 percent lower, respectively, than non-Hispanic white women (3). It is also consistent with previous studies which have demonstrated that poor women have a considerably lower risk of developing breast cancer than upper income women (10,11). However, the "protective" effect of factors associated with poverty is eliminated by the shift to late-stage disease, which results in women on Medi-Cal having the same risk of developing late-stage disease as women statewide.

These findings are similar to those reported by a study of breast cancer incidence in Connecticut in 1984-85, in which the rate among lower socioeconomic status (SES) women was 30 percent lower than among higher SES women, but the rate of metastatic disease was slightly higher (12). The authors estimated that 22 percent of breast cancer deaths among poor women were preventable by early detection, compared to 11 percent among upper SES women (12).

This study was limited by the inability to completely control for potential biases resulting from the selection of persons at increased risk for breast cancer into the Medi-Cal population. Restricting analyses to women covered by Medi-Cal for the entire year probably reduced this bias considerably in the calculation of incidence rates. The degree to which stage at diagnosis was biased upwards cannot be quantified. The study was also limited by the relatively high proportion of women of unknown race/ethnicity on the Medi-Cal eligibility file. Because of this, race-specific incidence rates in the non-Medi-Cal population could not be calculated. Since women on Medi-Cal are included in statewide rates, race-specific differences should be interpreted with caution. This is especially true for black and Hispanic women, who have a relatively large proportion of women on Medi-Cal.

This study may also be somewhat limited by the fact that the data are now five years old. However, invasive breast cancer incidence rates in California have been relatively stable since 1989 (3), and, according to the California Behavioral Risk Factor Survey (BRFS), a random-digit dial telephone survey conducted by the California Department of Health Services, breast cancer screening among women 40 to 64 years old in households with annual incomes below $15,000 has improved somewhat during the period 1990-1996, but is still substantially lower than among all other women (Figure 8) (2). Therefore, it is unlikely that these findings would be substantially different with more recent data.

Medi-Cal is expanding the number of beneficiaries who receive health care through managed care programs. One of the goals of this change is to increase the utilization of clinical preventive services (13). In 1993, about ten percent of Medi-Cal recipients were in managed care programs (13). This figure had increased to about 30 percent by 1997, and is expected to continue to increase. The success of Medi-Cal managed care in reducing the proportion of breast cancers diagnosed at late stage should be evaluated carefully.

This study provides strong evidence that women receiving health-care services through Medi-Cal are not being adequately screened for breast cancer, even though Medi-Cal pays for mammograms, or are not receiving timely follow-up after screening. Strategies must be developed and additional resources allocated to improve access to and utilization of breast cancer screening and follow-up services in this underserved population.

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Table 1. Number and percent of breast cancers diagnosed among women on Medi-Cal[1] by race/ethnicity[2] and stage at diagnosis[3], California women 30 to 64 years old, 1993

	All Breast Cancers			Late-Stage Breast Cancers		
	Statewide	Medi-Cal	% Medi-Cal	Statewide	Medi-Cal	% Medi-Cal
Asian/Other	828	90	10.9%	266	44	16.5%
Black	751	146	19.4%	286	75	26.2%
Hispanic	1,351	271	20.1%	577	146	25.3%
Non-Hispanic White	7,677	358	4.7%	2,473	177	7.2%
Unknown	139	2	1.4%	14	1	7.1%
Total	10,746	867	8.1%	3,616	443	12.3%

[1] Covered by Medi-Cal during at least one month in 1993 and not on Medicare in 1993.

[2] Race/ethnicity as reported to the California Cancer Registry. Categories are mutually exclusive. Persons of Hispanic ethnicity may be of any race.

[3] Late-stage tumors had spread beyond the breast to lymph nodes, adjacent tissues, or other organs when diagnosed.

Table 2. Diagnosis of breast cancer in Medi-Cal[1] women 30 to 64 years old in relation to Medi-Cal eligibility[2], California, 1993

	Cases	Percent
Diagnosed during a month eligible	714	82.4
Eligible entire 12 months	433	49.9
Eligible less than 12 months, but prior to diagnosis	144	16.6
Diagnosed in first month eligible	137	15.8
Diagnosed during a month not eligible	153	17.6
Eligible prior to diagnosis	18	2.1
Eligible after diagnosis only	135	15.6
1-2 months after diagnosis	76	8.8
3-5 months after diagnosis	36	4.2
6-11 months after diagnosis	23	2.7
Total	867	100

[1] Covered by Medi-Cal during at least one month in 1993 and was not on Medicare in 1993.
[2] "Eligible" means that the woman was covered by Medi-Cal.

Table 3. Number and percent of breast cancers diagnosed at late stage[1] by age at diagnosis and Medi-Cal status[2], California women 30 to 64 years old, 1993

Age	Women not on Medi-Cal			Women on Medi-Cal					
				Eligible for 12 Months			Eligible for less than 12 Months		
	Total Breast Cancers	Late Stage	% Late	Total Breast Cancers	Late Stage	% Late	Total Breast Cancers	Late Stage	% Late
30-34	284	131	46.1%	33	16	48.5%	30	21	70.0%
35-39	659	257	39.1%	53	24	45.3%	65	39	60.0%
40-44	1,308	464	35.5%	65	32	49.2%	81	41	50.6%
45-49	1,946	625	32.1%	83	38	45.8%	77	45	58.4%
50-54	1,902	582	30.6%	67	26	38.8%	63	39	61.9%
55-59	1,772	504	28.4%	62	26	41.9%	53	26	49.1%
60-64	2,008	610	30.4%	70	29	41.4%	65	41	63.1%
Total	9,879	3,173	32.1%	433	191	44.1%	434	252	58.1%

[1] Tumor had spread beyond the breast to lymph nodes, adjacent tissues, or other organs when diagnosed.

[2] Covered by Medi-Cal during at least one month in 1993 and was not on Medicare in 1993.

Table 4. Number and percent of breast cancers diagnosed at late stage[1] by race/ethnicity[2] and Medi-Cal status[3], California women 30 to 64 years old, 1993

Race/Ethnicity	Women not on Medi-Cal			Women on Medi-Cal					
				Eligible for 12 Months			Eligible for less than 12 Months		
	Total Breast Cancers	Late Stage	% Late	Total Breast Cancers	Late Stage	% Late	Total Breast Cancers	Late Stage	% Late
Asian/Other	738	222	30.1%	39	22	56.4%	51	22	43.1%
Black	605	211	34.9%	94	46	48.9%	52	29	55.8%
Hispanic	1,080	431	39.9%	113	46	40.7%	158	100	63.3%
Non-Hispanic White	7,319	2,279	31.4%	186	77	41.4%	172	100	58.1%
Unknown	137	13	9.5%	1	0		1	1	
Total	9,879	3,173	32.1%	433	191	44.1%	434	252	58.1%

[1] Tumor had spread beyond the breast to lymph nodes, adjacent tissues, or other organs when diagnosed.
[2] Race/ethnicity on the California Cancer Registry. Categories are mutually exclusive. Persons of Hispanic ethnicity may be of any race.
[3] Covered by Medi-Cal during at least one month in 1993 and was not on Medicare in 1993.

Table 5. Race-specific[1] prevalence ratios for late-stage[2] breast cancer, women on Medi-Cal[3] for 12 months compared to women not on Medi-Cal, California women 30 to 64 years old, 1993

	Prevalence Ratio	95% Confidence Interval
Asian/Other[4]	1.8	1.3 - 2.6
Black[4]	1.4	1.1 - 1.8
Hispanic[4]	1.0	0.8 - 1.3
Non-Hispanic White[4]	1.3	1.1 - 1.6
Total[5]	1.3	1.1 - 1.4

[1] Race/ethnicity on the California Cancer Registry. Categories are mutually exclusive. Persons of Hispanic ethnicity may be of any race.
[2] Tumor had spread beyond the breast to lymph nodes, adjacent tissues, or other organs when diagnosed.
[3] Covered by Medi-Cal during at least one month in 1993 and was not on Medicare in 1993.
[4] Controlling for age.
[5] Controlling for age and race/ethnicity, excluding women of unknown race/ethnicity.

Table 6. Breast cancer incidence rates statewide and among women on Medi-Cal for the entire year by age and stage[1] at diagnosis, California women age 30 to 64 years old, 1993

	All Breast Cancers			Late-Stage Breast Cancers		
	Rate per 100,000 women			Rate per 100,000 women		
Age at diagnosis	Statewide	Medi-Cal (12 months)	Medi-Cal Relative Risk	Statewide	Medi-Cal (12 months)	Medi-Cal Relative Risk
30-34	24.2	20.7	0.86	11.7	10.7	0.91
35-39	56.8	45.9	0.81	23.4	20.4	0.87
40-44	122.9	86.8	0.71	45.4	42.7	0.94
45-49	217.4	177.6	0.82	73.1	80.1	1.10
50-54	273.5	204.5	0.75	87.1	81.2	0.93
55-59	307.8	198.7	0.65	90.7	82.8	0.91
60-64	370.3	248.1	0.67	117.5	105.3	0.90
Age-adjusted rate[2]	156.0	113.9	0.73	52.5	49.9	0.95

[1] Late-stage tumors had spread beyond the breast to lymph nodes, adjacent tissues, or other organs when diagnosed.

[2] Age-adjusted to the 1993 California female population age 30 to 64 years old.

Table 7. Age-adjusted[1] breast cancer incidence rates per 100,000 population statewide and on Medi-Cal for the entire year by race/ethnicity and stage[2] at diagnosis, California women 30 to 64 years old, 1993

	All Breast Cancers			Late-Stage Breast Cancers		
	Rate per 100,000 women			Rate per 100,000 women		
Race/Ethnicity	Statewide	Medi-Cal (12 months)	Medi-Cal Relative Risk	Statewide	Medi-Cal (12 months)	Medi-Cal Relative Risk
Asian/Other	108.2	76.2	0.70	34.6	39.4	0.88
Black	163.0	147.3	0.90	61.9	70.6	0.88
Hispanic	104.6	81.7	0.71	44.0	36.9	1.19
Non-Hispanic White	174.1	134.6	0.78	56.4	58.0	0.97
Unknown		95.4			47.8	
All Races	156.0	113.9	0.73	52.5	49.9	0.95

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[1] Age-adjusted to the 1993 California female population age 30 to 64 years old.

[2] Late-stage tumors had spread beyond the breast to lymph nodes, adjacent tissues, or other organs when diagnosed.

APPENDIX IV

Allen M, Perkins CI, Wright WE. Using Medicare administrative files to evaluate case ascertainment in a central cancer registry. J Reg Mgmt. 1998; 25(1):13-16.

Using Medicare Administrative Files to Evaluate Case Ascertainment in a Central Cancer Registry

Mark Allen, MS; Carin I. Perkins, MS; William E. Wright, PhD

Abstract: **The recent increase in outpatient treatment of cancer patients poses difficulties for central cancer registries, which historically have relied on hospitals for case ascertainment. Medicare administrative files for fee-for-service recipients were used to identify female California residents age 65 and older who received breast cancer surgery during 1993 as inpatients or outpatients. Medicare beneficiaries were then matched to breast cancer cases on the California Cancer Registry (CCR). Follow-back was conducted on Medicare beneficiaries who were not identified on the registry. Of the 6,241 fee-for-service Medicare clients, 5,982 (95.9%) were matched to a case on the CCR through computerized linkage. Of the 259 non-matches, 13.9% were on regional registry databases; 49.4% were not reportable; 24.3% were reportable breast cancer cases; and 12.4% were unresolved. The majority of unreported cases had been missed because of random, rather than systematic, errors. Case ascertainment was somewhat higher among Medicare women treated as inpatients (98.8%) than as outpatients (97.4%). Given the current level of non-hospital case reporting in California, linkage with the Medicare administrative files on a routine basis does not seem to be merited for case ascertainment. However, central registries with less complete reporting from non-hospital facilities might find linkage with Medicare files, particularly those from outpatient visits, more fruitful for case ascertainment.**

***Key words*: central cancer registry, casefinding, completeness, administrative files**

Introduction

An increasing proportion of cancer patients are being treated on an outpatient basis. The age-adjusted hospital discharge rate for primary diagnoses of cancer declined by more than ten percent over the five-year period 1988 to 1992.[1] The Centers for Disease Control and Prevention National Cancer Registries Program estimates that about ten percent of cancer patients are not seen as inpatients. This poses particular difficulties for central cancer registries that historically have relied on hospitals for case ascertainment.

Cancer reporting in California is mandatory.[2] Patients not admitted to hospitals are required by law to be reported to the statewide registry by the treatment facility or physician.[3] In practice, cancer patients not admitted to hospitals in California are usually identified through active surveillance at pathology laboratories and non-hospital facilities such as ambulatory surgery centers. Case ascertainment through non-hospital sources is complicated by the large number of potential facilities and their relatively high turnover in a competitive market. The use of high-volume, out-of-state pathology laboratories by managed care organizations also poses potential barriers to complete case ascertainment, as these facilities are not covered by the California Cancer Reporting Act. Thus, as patient treatment moves into the environment of the outpatient setting and managed care, concerns over the completeness of case ascertainment arise.

The California Cancer Registry was particularly concerned about ascertainment of breast cancer cases diagnosed in 1993. Since the implementation of statewide cancer reporting in 1988, the number of invasive breast cancers had increased fairly steadily each year, primarily reflecting the aging of the California population during a period of stable breast cancer incidence rates. However, in the fall of 1995, only 17,616 invasive breast cancers had been reported for 1993, which was 2.3% lower than the number of cases reported at that time for 1992. The decline in cases was somewhat higher for women age 65 and older (2.6%) than among younger women (2.0%).

About one-half of breast cancers in California are diagnosed among women 65 years old and older[4], and 96% of persons 65 and older are covered by Medicare[5]. The Health Care Financing Administration (HCFA) maintains databases of Medicare claims, including those from outpatient facilities, and therefore offers a unique source of information on patients who may be missed by hospital-based registries.

This study was undertaken to assess the extent to which incomplete case ascertainment contributed to the apparent decrease in breast cancer case reporting among women age 65 and older in California. HCFA administrative files were used to identify female California residents age 65 and older who received breast cancer surgery during 1993 as hospital inpatients or at ambulatory surgery centers. Medicare beneficiaries were then matched to women diagnosed with breast cancer

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"Using Medicare Administrative Files to Evaluate Case Ascertainment in a Central Cancer Registry"
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on the California Cancer Registry (CCR). Follow-back was conducted on all Medicare beneficiaries with breast cancer who had breast surgery, but had not been reported to the registry, to ascertain whether the case was, in fact, a reportable cancer.

Methodology

This study was conducted as part of a larger collaborative effort between HCFA and the California Department of Health Services to evaluate breast cancer treatment and outcomes in the Medicare population.[6]

HCFA File

HCFA inpatient (Part A) claims and outpatient (Part B) claims from ambulatory surgery centers, including outpatient hospital services, were used to identify female California residents age 65 and older who had breast cancer and received breast surgery during 1993. Women who had a main or first diagnosis of invasive or *in situ* breast cancer and a treatment code for breast surgery were selected (see Appendix). Claims data were not available on Medicare beneficiaries in managed care plans, who accounted for approximately 30-35% of Medicare participants in California.[6] California residents whose claims arose from an out-of-state physician or facility were included.

HCFA provided the CCR with the names and other relevant information on the 7,516 Medicare beneficiaries meeting the above selection criteria. When records missing a last name and women appearing on both Part A and Part B files were consolidated, 6,241 individuals remained. Of these, 4,748 were treated at hospitals only or at both hospitals and ambulatory surgery centers, and 1,493 were treated at ambulatory surgery centers only.

CCR Data

The CCR is a statewide, population-based cancer registry. Ten regional registries submit cases to the CCR on a quarterly basis. Although reporting has been statewide since 1988, several regional registries were collecting population-based incidence data prior to that date. About half of the state was covered by population-based registries in 1987, and the five counties in the San Francisco Bay Area have participated since 1973 in the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute.

For this study, all female breast cancers reported to the CCR as of October 1995 and resident within the reporting region were included in the linkage. Cases were not selected on year of diagnosis, since cases treated in 1993 could have been diagnosed at an earlier date. Overall cancer reporting for 1993 was estimated to be 96.7% complete as of October 1995. A total of 188,021 cases met the selection criteria, 10.5% of which were *in situ* tumors. A total of 20,121 female breast cancers were diagnosed in 1993, 12.4% of which were *in situ* tumors.

Linkage

The software program AUTOMATCH was used to perform a probabilistic linkage of the HCFA and CCR files.[7] Social security number, patient name, date of birth, address, zip code, and dates of admission and discharge were used in the linkage process. AUTOMATCH assigns a probability score based on the degree of similarity in the linkage variables. User-defined cutpoints define matches and those which require visual review. About 87% of the matched records were an exact match on the social security number with all variables used to confirm a match. Another 7% of the matched records were exact on phonetic (NYSIIS) coding of the first and last name, but had small discrepancies in (or unknown) social security numbers. The remaining 6% of matched records were not exact on either social security number or phonetic coding of name, but were reviewed visually using all available information and evaluated as a match.

Follow-back

Relevant information on Medicare clients treated for breast cancer in 1993 but not identified as cancer patients on the CCR through the initial linkage was sent to the regional registry responsible for data collection in the geographic area where Medicare records stated that the client was living when surgery was performed. This took place in January 1996, about four months after cases used in the initial linkage had been submitted to the CCR. Regional registries were provided with patient name, date of birth, address, admission date, discharge date, date of death if applicable, and provider name and address. Regional registries first checked their active and suspense databases to ascertain if the case had been reported since the quarterly submission used in the linkage, or if the linkage methodology had failed to identify the patient.

If the individual was not found on the regional databases, follow-back was initiated at the treatment facility. Results of follow-back were recorded on a survey instrument designed for the study. Approximately six months were allowed for follow-back to be completed.

Results

Of the 6,241 women identified by Medicare as receiving surgery for breast cancer in 1993, 5,982 (95.9%) were identified as breast cancer cases on the CCR through the initial linkage (Table 1). Of those identified on the CCR, the majority (88.0%) were diagnosed with breast cancer in 1993; 1.2% were diagnosed prior to 1988, 3.7% in 1988-1991, and 7.0% in 1992.

Among the 4,748 Medicare clients treated as inpatients, 4,599 (96.9%) were identified on the CCR through the initial linkage, compared to 1,383 (92.6%) of the 1,493 women receiving surgery on an outpatient basis only (Table 1).

Of the 259 Medicare clients not matched to a case on the CCR through the initial linkage, 36 (13.9%) were, in fact, identified on the regional registry databases before follow-back was initiated (Table 2). Twenty-one of these cases had been reported to the regional registries for the first time between October 1995 and the initiation of follow-back. Another 15 cases were on the submission used in the linkage, but failed to be matched. About half of these had been excluded from the linkage at the beginning of the process because the CCR had the gender coded incorrectly as male. Other cases failed to be matched because of variations in name, date of birth, or social security number which resulted in probability scores below the cutpoint for visual review.

Follow-back on about half (49.4%) of the Medicare beneficiaries not originally linked to the CCR indicated that the case was not reportable because the patient was not a California resident at the time of diagnosis, diagnosis was prior to the reference date for the regional registry, or the client did not have breast cancer (Table 2). The majority (75%) of Medicare clients in follow-back who were determined by registry standards not to have breast cancer had surgery as an outpatient only.

Table 1. Outcome of initial linkage between CCR breast cancer cases and Medicare breast cancer clients receiving breast surgery in 1993 as an inpatient or outpatient

	Medicare Clients	Linkage Results: Matched to Case on CCR		Not Matched
	No.	No.	Percent	No.
Inpatient Surgery	4,748	4,599	96.9%	149
Outpatient Surgery	1,493	1,383	92.6%	110
Total	6,241	5,982	95.9%	259

Table 2. Outcome of follow-back on Medicare breast cancer surgery patients not matched to a case on the CCR

	Inpatient		Outpatient		Total	
	No.	%	No.	%	No.	%
Total Cases Sent to Regional Registries	149	100%	110	100%	259	100%
On CCR before follow-back initiated	22	14.8%	14	12.7%	36	13.9%
Added after linkage but before follow-back	10	6.7%	11	10.0%	21	8.1%
Failed to be matched	12	8.1%	3	2.7%	15	5.8%
Follow-Back Outcome						
Not Reportable	70	47.0%	58	52.7%	128	49.4%
Not a resident	39	26.2%	22	20.0%	61	23.6%
Dx prior to reference date	24	16.1%	15	13.6%	39	15.1%
Not breast cancer	7	4.7%	21	19.1%	28	10.8%
Not Resolved	30	20.1%	2	1.8%	32	12.4%
Out of state facility	30	20.1%	1	0.9%	31	12.0%
No record at facility	0	0%	1	0.9%	1	0.4%
New Cases	27	18.1%	36	32.7%	63	24.3%
Missed by abstractor	22	14.8%	16	14.5%	38	15.1%
Not transmitted	5	3.4%	1	0.9%	6	1.9%
Pathology lab non-reporting	0	0%	16	14.5%	16	6.2%
MD non-reporting	0	0%	3	2.7%	3	1.2%

Reporting status of 12.4% of the Medicare clients could not be resolved; all but one of these had been treated at an out-of-state facility, and a decision was made not to pursue follow-back at these facilities due to difficulties in sharing confidential data between states.

Of the 259 Medicare clients not found in the original linkage, a total of 63 (24.3%) were cases that should have been reported to the CCR. Nearly 70% of these missed cases had, in fact, been seen either at a hospital or another facility where active surveillance was routinely conducted by the regional registry. A few cases were on a hospital cancer registry, but reporting to the regional registry had not occurred, probably due to technical difficulties. About 25% of the missed cases should have been identified through active surveillance at pathology labs, but were not because of recognized difficulties with the specific laboratories. Only three of the missed cases were "Physician Only" cases, i.e., would not have been identified through routine reporting of non-hospital facilities or active surveillance. All of the cases missed because of failures to report from pathology laboratories or physicians had surgery on an outpatient basis only.

Of the 63 newly identified cases, 53 (84.1%) were diagnosed in 1993, 36 (57.1%) received breast cancer surgery as an outpatient only during 1993 according to the HCFA files, and 12 (19.0%) were *in situ* tumors.

Discussion

Many central registries routinely use administrative files from various sources including HCFA inpatient files for passive follow-up. However, HCFA files, especially those for outpatient services, have not been routinely used for case ascertainment.

This study reassured the CCR that breast cancer case ascertainment in the Medicare fee-for-service population was quite high for women undergoing breast surgery in California. If one assumes that all cases with unresolved follow-back were, in fact, reportable to the CCR, 98.4% (6,018 out of 6,113) of Medicare beneficiaries who should have been on the registry were reported before follow-back for this study was initiated. If one assumes that cases with unresolved follow-back would not be reportable, 99.0% (6,018 out of 6,081) of Medicare beneficiaries were reported.

Medicare clients receiving surgery on an outpatient basis only were less likely to be found on the initial linkage with the CCR than Medicare inpatients (92.6% and 96.9%, respectively) (Table 1). Among Medicare clients not found in the initial linkage, 18.1% of cases seen as inpatients were judged to be reportable at the completion of follow-back, compared to 32.7% of outpatients. However, the proportion of reportable cases among inpatients might have been higher if follow-back had included out-of-state hospitals, since all but two cases with unresolved follow-back were treated at an out-of-state hospital.

The follow-back efforts in this subgroup of cancer patients did not, however, result in a substantial increase in new cases. Adding the 53 newly identified cases diagnosed in 1993 to the CCR increased the number of female breast cancers for 1993 from 20,121 to 20,174 (0.3% increase). Given the current level of active surveillance and non-hospital case reporting in California, linkage with the HCFA administrative files on a routine basis does not seem to be merited for case ascertainment, given the efforts involved in follow-back on non-matching cases. These conclusions are similar to those reported by the Ontario Cancer Registry, which estimated that the proportion of unreported cases from day surgery records was 0.6% of registered cases.[8] However, registries with less active surveillance at non-hospital facilities might find the HCFA administrative files more fruitful for case ascertainment, particularly those from outpatient visits.

Nonetheless, the study was useful for the CCR as a one-time undertaking because a number of failures in case ascertainment were identified and can be acted on. For example, follow-back was not pursued in out-of-state facilities, but it is likely that California residents who are diagnosed and/or treated in out-of-state facilities are under-reported. Steps have been taken to improve exchange of confidential information between the CCR and other state registries and facilities. In addition, follow-back efforts for this study identified a pathology laboratory where active surveillance was taking place, but was not capturing a subset of its clients that it considered "private." Clarification of this issue will improve communication with other pathology laboratories as well as the specific laboratory in question. There was no evidence that use of out-of-state pathology laboratories was impacting negatively on case ascertainment in this subset of patients; this was a concern going into the study.

The majority of other failures in case ascertainment appeared to have resulted from random, rather than systematic, problems. Assuming that the 30 Medicare beneficiaries treated at out-of-state hospitals should have been reported to the CCR, completeness of case reporting at hospitals for this subset of patients was quite high (4,621 of 4,678, 98.8%), and was very similar to that reported by SEER from a casefinding audit conducted at hospitals in 1987 (97%).[9] Case reporting for fee-for-service Medicare clients seen as outpatients only was only somewhat lower (1,397 of 1,435, 97.4%), but still quite high.

This study has a number of limitations. In particular, the subset of women in this study (fee-for-service Medicare clients age 65 and older) accounted for approximately one-third of breast cancer cases in California. It is possible that case-reporting was less complete for women covered by Medicare managed care programs (approximately 15% of cases) and/or younger women (about 50% of cases). It was not possible to identify managed care Medicare clients receiving breast surgery, since claims for specific procedures are not submitted to HCFA. It also was not possible to verify that the number of breast cancer cases among fee-for-service Medicare women declined between 1992 and 1993, since HCFA administrative files for the collaborative study mentioned above were only obtained for 1993.

In addition, the findings of this study may not apply to other cancer sites, especially those known to have a high proportion of cases treated on an outpatient basis, such as melanoma of the skin. Finally, the use of out-of-state pathology laboratories and outpatient treatment may have increased since 1993.

It is worth noting that of the 6,241 Medicare women in the study, 1,493 (23.9%) had breast surgery in 1993 on an outpatient basis only. Although a woman may have been an inpatient for some other treatment modality during 1993, or for breast surgery during a different calendar year, this does indicate that a relatively high proportion of breast cancer surgeries covered by fee-for-service Medicare are taking place on an outpatient basis. Central registries which rely on inpatient data for case ascertainment are more likely to miss these cases. New standards adopted by the Commission on Cancer that require hospital registries to include data from physician's offices were motivated by this new reality in health care.[10]

The vast majority (95.0%) of Medicare women receiving breast surgery in 1993 were diagnosed with breast cancer in 1992 or 1993. Recently established central registries who use HCFA administrative files for case ascertainment may find that a considerable effort is expended on follow-back for cases that were diagnosed prior to the registry's reference date.

In summary, Medicare administrative files were successfully used to evaluate completeness of breast cancer case reporting on the CCR of women age 65 and older covered by Medicare on a fee-for-service basis; the files were not especially useful in identifying new cases. It is not clear whether the results of this study apply to other cancer sites, to Medicare recipients in managed care plans, or to younger women. The number of breast cancers reported in California for 1993 is still about 1.7% lower than for 1992.[4] Whether this reflects a true decrease in the risk of developing breast cancer or unidentified shortcomings in case ascertainment cannot be determined.

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Appendix

Diagnostic and surgical codes used to select claims on HCFA administrative files.

Part A Files

Main or first diagnosis:
ICD-9-CM codes 174.0-174.9 or 230.0

and

Procedure 1 through 10:
ICD-9-CM surgical codes 85.21-85.25, 85.33-85.36, or 85.41-85.48

Part B Files

Main or first diagnosis:
ICD-9-CM code 174.0 - 174.9 or 230.0

and

Procedure:
1993 Physician's Current Procedure Terminology (CPT) codes 19120, 19160, 19162, 19180, 19182, 19200, 19220 or 19240.

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UNITED STATES OF AMERICA

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FOR THE COMMANDER:

Phylis Rinehart
PHYLIS M. RINEHART
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