AN EVALUATION OF THE SYSTEM USED BY THE BRITISH COLUMBIA CANCER REGISTRY TO RECORD DATA ON CASES OF INVASIVE CERVICAL CANCER.

by

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Abstract

This study evaluated the quality of data recorded by the British Columbia (B.C.) Cancer Registry on cases of invasive cervical cancer. This study did this by comparing the Registry's pathological diagnosis, age, marital status, residence, and date of death of all cases that had been registered as invasive cervical cancer in B.C. during 1977, 1978, and 1979 with a best estimate of the truth for these items of information, based on data collected from B.C.'s cytology screening programme and from clinical charts on file at the Cancer Control Agency of British Columbia (C.C.A.B.C.).

This comparison showed that the Registry's data for these years over-estimated the true incidence of invasive cervical cancer. One hundred and eighty-four (35%) of the Registry's 521 cases were not true cases of invasive cervical cancer. Of these 184, 141 (77%) were cases of pre-invasive cervical cancer; 26 (14%) did not fit the criteria of an incident case (a new case of invasive cervical cancer diagnosed in B.C. during 1977 to 1979); and 17 (9%) were cases of invasive cancer of another primary site (e.g. bowel, endometrium). In addition to this misreporting, 28 true cases of invasive cervical cancer that had been diagnosed in B.C. during 1977 to 1979 had not been reported to the Registry. Thus, there were errors of omission as well as commission.

Finally, it was found that the Registry only recorded 25 (29%) of the 85 fatalities that had occurred among the true cases of invasive cervical cancer, and that the information on marital status was incorrect for 65% of cases, and, on residence for 30%. Further investigation revealed that all of these inaccuracies arose because of unsatisfactory registration procedures used by the Registry.

In conclusion, the results of this study indicate that there have been

shortcomings in the data provided by the B.C. Cancer Registry for use in monitoring the incidence of this type of cancer over time; in planning service facilities for it; and evaluating the provincial cervical screening programme.

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CHAPTER I: INTRODUCTION

In developed countries cancer is an important health problem. It is one of the major causes of death and disease in these populations. Numerous efforts are therefore being made to learn more about the nature and extent of cancer. It is hoped that the increased knowledge will lead to improved methods of prevention, diagnosis and treatment of cancer and will ultimately reduce its morbidity and mortality.

These efforts require accurate and reliable information on the magnitude of the cancer problem; its distribution in various subgroups of the population (age, sex, residence, occupation and so forth); and the course and outcome of the illness in individuals diagnosed with cancer. One of the major sources of such information is a cancer registry. Typically, a cancer registry collects and stores, on an ongoing basis, a range of data relating to individual cases of cancer in a well defined population (hospital, province, country). It also analyzes these recorded data and produces statistics on incidence* and mortality from cancer by site, sex, and age.

These data can be used to look for upward or downward trends in the incidence of a specific type of cancer. For example, in British Columbia (B.C.) recorded data from the provincial cancer registry was recently used to examine the trend in incidence of invasive cervical cancer (Gallagher, R. and Elwood, M. 1982). This study showed that incidence of this invasive cancer among women aged 15-44 since 1974 was increasing in spite of widespread use of a provincial cervical cytology screening programme by young B.C. women. Similar reports have appeared elsewhere in the literature (Yule 1978; Andrews et al 1978; Antello et al 1979; Berkowitz et al 1979; Green 1979;

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* For definition of technical terms, see Appendix I.

Prendiville et al 1980; Berkley et al 1980). These reports prompt some queries: is the increase due to improved diagnosis (especially since the introduction of colposcopy)? improved notification? a changing natural history of the disease with a truly increased incidence?

However, figures produced by the B.C. cervical cytology screening programme differed in that they showed a decreased incidence among women over 20 between 1955 and 1977 (Boyes et al 1981). This downward trend has also been reported in other areas (Walton Report 1976; McGregor et al 1974).

In an attempt to resolve this discrepancy in the reported incidence of invasive cervical cancer in B.C. it was decided to evaluate the quality of data recorded by the B.C. Cancer Registry on cases of invasive cervical cancer.

The main objective was to find out if the Registry was over-reporting the number of new cases of invasive cervical cancer and therefore over-estimating the incidence of this disease. A secondary objective was to assess the quality of the follow-up (case fatalities) and some of the demographic information (age, marital status, residence) recorded by the Registry on cases of invasive cervical cancer.

It was anticipated that this study's findings would form the basis for remedial action and improved functioning of the B.C. Registry.

CHAPTER 2: BACKGROUND

This chapter is divided into three sections. The first gives a short history of cancer registries. The second provides a history of the B.C. population based Cancer Registry. The third gives some background on the provincial cervical cancer screening programme and its link with the B.C. Cancer Registry.

2.1 Cancer Registries

2.1.1 Aims

The broad aim of a cancer registry is to collect, to store, and to report accurate and reliable data that can be used in cancer research and in planning, administering and evaluating cancer programmes. Traditionally, most registries have accomplished this by annually: (1) ascertaining the number of new cancers diagnosed in a defined population; (2) calculating the incidence rates of these new cases of cancers; (3) determining the number of deaths from cancers in a defined population; and (4) calculating mortality rates of these cancers.

In the last 10 to 20 years efforts have been made by many registries to increase the range of information compiled and generated by them in order to achieve their broad aims more effectively. (Knowelden et al 1970; Haenszel 1975; Barclay 1975; Grundmann 1975; Waterhouse 1980; Saxen 1980). These efforts were instigated mainly by a criticism (Pedersen 1962; Staszewski 1975; Elwood and Gallagher 1980) that cancer registries, although consuming health care dollars, were generating information which was either of limited value and/or already available from existing data banks (e.g. census and health insurance data). In some registries these efforts have resulted in additional information being collected and published, for example, data on the registered cases' treatment and follow-up and survival statistics.

2.1.2 Methods of Registration

Prior to the 1960s these methods varied widely among the operating cancer registries in the world. However, in the late 1960's, findings from research sponsored by the International Union Against Cancer (UICC) encouraged registries to develop standardized methods of operation. This research revealed that the data from various international registries could not be compared because of wide discrepancies in their registration procedures. The primary source of diagnostic information, for example, was frequently not the same. Some registries used death certificates to ascertain new cases of cancer, while others used laboratory reports from pathology and/or cytology investigations. The diagnosis of new cases of cancer obtained from laboratory reports was usually regarded as more reliable than information from death certificates because the latter was written at the terminal stage of the disease by attending physicians who sometimes did not have access to all medical information on cases (e.g. pathology reports, clinical records). This was necessary to record accurately the cancer site, type and behaviour and date of diagnosis. The reliability of recorded diagnoses therefore varied between registries and this limited the comparability of registries' data, specifically with respect to incidence of different types of cancer. Furthermore, the systems of cancer classification were often different as were the methods used to calculate the incidence and survival rates and the definitions of the variables (personal and clinical) used to describe the cases. These differences further reduced comparability of registries' data. Subsequently, individuals and agencies (international and national) published works discussing the materials and methods that were necessary to ensure that a registry's information was complete, accurate, and comparable. (Angelsio 1975; Barnes et al 1975; Tuyns 1975; World Health Organization (WHO) 1976 a and b; Fujimoto et al 1977; International Agency

for Research on Cancer (IARC) and International Association of Cancer Registries (IACR) 1978; Saxen 1980; Waterhouse 1980). In Canada, the National Cancer Institute (1975) printed a manual, giving guidelines for planning and operating a registry that will produce good data.

2.1.3 Evaluation

The need for assessing the quality of a registry's recorded information has recently been emphasized in the literature. (WHO 1979; Elwood and Gallagher 1980). Past studies measuring the quality of the data (Barclay 1975; IACR and IACR 1976) judged the performance level from the percent of histological confirmations and/or the percent of death notifications. A high ratio of pathology diagnoses to death registrations implied good data. Yet they recognized that inferences made about the grade of a registry's output should be based on an assessment which determines if: one, the recorded pathological diagnosis is the most valid; two, the cancers are coded correctly in view of site, type and behaviour; and three, the registration is complete. Moreover, they recommended that registries should start to do this type of assessment in order to monitor the quality of data that are produced by them, thereby supporting this evaluation of some of the B.C. Registry's recorded data on cases of invasive cervical cancer.

2.2 History of the B.C. Cancer Registry

This Registry has been in operation since 1966. Prior to April 1980 it was located in the Provincial Division of Vital Statistics. At this time it was transferred to the Division of Data Services of the Cancer Control Agency of B.C. (C.C.A.B.C.) who assumed responsibility for its functioning.

2.2.1 Aims

These are:

(1) to ascertain all cases of invasive and in situ cancers, diagnosed in B.C.;

(2) to calculate incidence and prevalence rates, by age and sex, of invasive and in situ cancers diagnosed in B.C.;

(3) to calculate survival rates for all cases of invasive and in situ cancers diagnosed in B.C.; and

(4) to collect demographic and follow-up data on cases for epidemiological and clinical studies.

In the past the Registry has primarily focussed on accomplishing the first 2 aims. However, with its relocation to the C.C.A.B.C. in 1980 planning and organization is being done by Registry personnel, in order to achieve the other two aims.

2.2.2. Methods of Registration

In B.C., cancer has been a notifiable disease since 1932. An actual reporting system was implemented in 1935. From 1935 to 1966 this system was based on direct notification from private physicians to the Provincial Division of Vital Statistics. In 1966, these notifications were redirected to the newly established B.C. Cancer Registry. However, reporting of new cases of cancers by physicians was never complete. In 1968, 30% of the cancers were still registered by a death certificate. In order to correct this it was decided by the Registry to request copies of all pathology reports that mentioned cancer from pathology laboratories in B.C. Thus, since 1969 the Registry's notifying system has been primarily based on pathology reports. Additional reporting sources are death notifications, sent to the Registry from the Provincial Division of Vital Statistics; private physicians; C.C.A.B.C. cancer treatment centres, and hospital medical records departments. The most recent figures published by the Registry stated that a pathology report was used to register 82.8% of all cases of cancer, recorded as being diagnosed in B.C. during 1978; a death notification was the sole source for 10.9% of cases; private physicians, cancer treatment centres or hospital medical

records departments accounted for 6.3% of them.

The first pathology report (or other type of report) received by the Registry for a new case of cancer is the one that is used to register this case. The cancer diagnosis and the identifying and demographic variables (name, address, age, sex, marital status) from this report are the data that are coded and stored on magnetic tape for each new case of cancer. It should be mentioned that all the diagnoses are classified according to the International Classification of Diseases for Oncology (IDC-O).

Follow-up of the registered cases involves recording data and cause of death. These data are collected from the lists of deaths in B.C. that are compiled by the Provincial Department of Vital Statistics monthly and sent to the Registry. Registry staff manually compare these death listings with the Registry's master list in order to ascertain the deaths that occurred among cases and the dates and causes of these deaths.

Other diagnostic information that is generated on cases after their initial registration and sent to the Registry is not necessarily entered into case computer files. In order to avoid the danger of underascertainment of new cases of invasive cancer, the Registry adopted a policy some years ago of accepting the most serious pathological classification. Thus, if the Registry's initial diagnosis was of an invasive cancer, and subsequently a diagnosis of non invasive cancer was received the first diagnosis was left unchanged. On the other hand, if the initial diagnosis was benign or pre-invasive cancer, and a subsequent one was invasive the Registry entry would be upgraded.

Every year the Registry publishes a report containing data on the annual number of new cases of cancer diagnosed in B.C. and of the deaths in B.C. from cancers by age and sex. Annual incidence and mortality rates by age and sex are also produced.

2.2.3 Evaluation

The Registry has not yet developed routine procedures for assessing the quality of its recorded data. Some of the publications (C.C.A.B.C. 1980; McBride 1981) on the Registry have inferred that diagnostic data on its cases are good by drawing attention to the high ratio of diagnoses made from pathology reports to those made from death notifications. As outlined earlier, this ratio is widely used in other parts of the world as an indicator of registry performance.

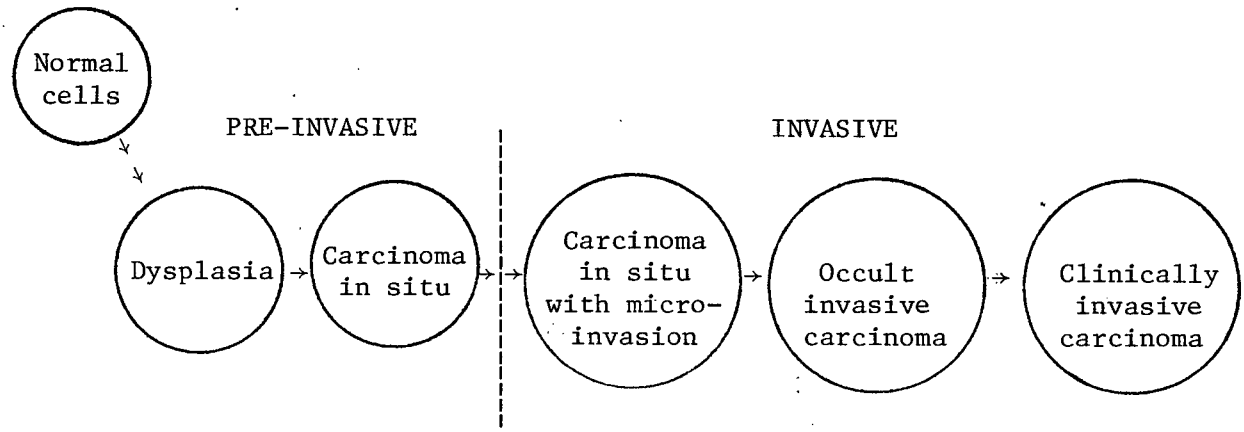
2.3 The History of the Provincial Cervical Cancer Screening Programme and its link with the B.C. Cancer Registry

In 1949 a cytology programme was introduced and subsequently a province wide programme was developed in B.C. for all women over the age of 20 years in the province. The objective of the programme was to determine if cytologic screening by Papanicolaou smears would result in a decrease in both the incidence and mortality of invasive cancer of the cervix in B.C.

This mass screening programme was justified by the commonly accepted models of the natural history of cervical cancer (Figure 2.3.1). This model shows that cancer of the cervix develops as a sequence of events, progressing with time. Normal cervical cells change to dysplastic cells; dysplasia to in situ cancer; and finally, in situ to invasive cancer. Current thinking is that this may take place over a period of approximately 10 to 20 years or more, although in some cases the time interval is considerably shorter. It also implies that there is a latent period within this natural history during which cervical cancer can be identified, diagnosed and treated prior to invasion, up to and including in situ cancer.

This model provided the rationale for the cytology screening programme. By means of a Papanicolaou smear (see Appendix I) within an apparently well female population, women can be identified who possibly have a pre-invasive

Figure 2.3.1 - Natural history of invasive cervical cancer.



See Appendix I for definitions of above precancerous and cancerous lesions.

cancer and further diagnostic procedures can confirm or refute this provisional diagnosis. In B.C., the cytology report from a Papanicolaou smear is sent to the woman's private physician. It gives information on the type of cervical cells detected (for example, normal or dysplastic or cells with cancer characteristics) and also makes a recommendation for further management, for example, a repeat smear in 3 months or a diagnostic colposcopy. These two functions of the B.C. screening programme could help to reduce the incidence and mortality from invasive cancer of the cervix because they would prevent cases of preinvasive cancers progressing to invasive cancers.

In order to evaluate the success of screening in achieving this objective, the provincial cytology programme has reported annually (1962-1977) incidence and mortality rates of clinically invasive squamous cancer of the cervix in B.C. These figures show a consistent decrease in both rates. (Boyes et al 1981). The numerator data for these calculations were collected by requesting diagnostic and death information from the provincial pathology laboratories and/or the C.C.A.B.C. treatment centres and/or the Cancer Registry. The data that were received from these sources were assessed for accuracy (by checking the cases' clinical chart or contacting their private physician or reviewing the pathology slides) before they were recorded by the screening programme. This procedure led to a suspicion that the registry was over-reporting the number of new cases of invasive cervical cancer diagnosed in B.C.

CHAPTER 3: MATERIALS AND METHOD

The data for this evaluation came from three sources. The first source was the B.C. Cancer Registry which collects information on a range of variables for all cases of invasive, borderline invasive, and in situ cancers, diagnosed in British Columbia. The second was the provincial cervical cytology screening programme which compiles clinical, cytological and pathological information on women in B.C. who have had a Pap smear. The third source was the clinical chart of the cancer treatment centres which contains personal, diagnostic and clinical information on cases of cancers that are referred to these centres for diagnosis and/or treatment.

The evaluation compared the Registry's pathological diagnosis, age, marital status, residence and date of death of all the cases that it had recorded as being diagnosed with invasive cancer of the cervix in 1977, 1978, and 1979 with a "best estimate" of the "truth" for these 5 variables. This was based on data collected from the cytology screening programme and the clinical chart. Only three years of the Registry's total output were assessed because of the lack of time to validate all the recorded data available since 1969. Also, looking at these specific years would help the cytology screening programme by updating the incidence statistics on clinically invasive squamous cell cancer of the cervix.

The Registry's research officer produced a master list that gave the name, pathology diagnosis, age, marital status, residence and date of death for every case of invasive cervical cancer diagnosed in 1977, 1978 and 1979. In addition, other information such as: the date of diagnosis, source of report, date of report, and method of diagnosis was included on this master list because it was felt that these variables might help to identify the reasons for any misclassifications of pathological diagnoses by the Registry.

The cytology programme keeps a card file for every case of cancer of the cervix. This file contains all the pathology reports generated during the diagnosis and treatment of the case. It was therefore not necessary to contact hospitals and/or practitioners in order to locate the pathology reports that were used to confirm or to refute the Registry's pathological diagnosis.

Another source of information was the clinical chart from the Vancouver or Victoria treatment centres. This was used to gather additional demographic data, the date of death and the autopsy report because the records in the cytology department often did not have complete information on these variables. Each chart had an admission sheet giving the age, marital status and residence and, when applicable, it also contained the death certificate (and thus the date of death) and the autopsy report, if an autopsy was performed.

An abstract form (Appendix II) was developed to code the data received from the Registry and other sources of data for this evaluation.

An analysis was then carried out, comparing the Registry's information on age, residence, marital status, date of death and pathological diagnosis with that from the other sources. Then, a review of the pathology reports from which the misreported cases were registered was made in order to learn the causes of the Registry's misreporting.

CHAPTER 4: RESULTS

Sections 4.1 to 4.3 give the results of the comparison of the Registry's pathological diagnosis with the best estimate of the true pathological diagnosis based on the cytology records and clinical charts. Section 4.4 and 4.5 give the results of the comparison of the Registry' information on date of death, age, marital status and residence with the best estimate from other sources.

4.1 The Pilot Study

A pilot study was carried out on a sample of 11% of Registry cases to ensure that it was possible to establish a valid diagnosis from the case files in the cytology department and that the pathology codes that were used in this evaluation's abstract form adequately represented all the types of cervical cancer likely to be encountered.

The first finding (Table 4.1.1) was that 20 (35%) of the Registry's 57 diagnoses were inaccurate. Table 4.1.2 shows that in 15 cases the true diagnosis was pre-invasive cancer (carcinoma in situ); in 3 cases the primary site of the invasive cancer was not the cervix; and the other 2 cases did not meet the Registry's criteria for an incident case (a new case of invasive cervical cancer diagnosed in B.C. during 1977 to 1979).

The second finding was that more than one pathology report was often needed to establish a valid pathological diagnosis of cancer of the cervix. As illustrated in the diagram (Figure 4.4.1) there are a number of places where the final diagnosis may be changed from the one based on the first biopsy. For example, the diagnosis from a colposcopy may alter following a cone biopsy and/or hysterectomy.

This was an important finding because it explained why 18 (90%) of the misreported cases discovered in the pilot test had occurred. The Registry's

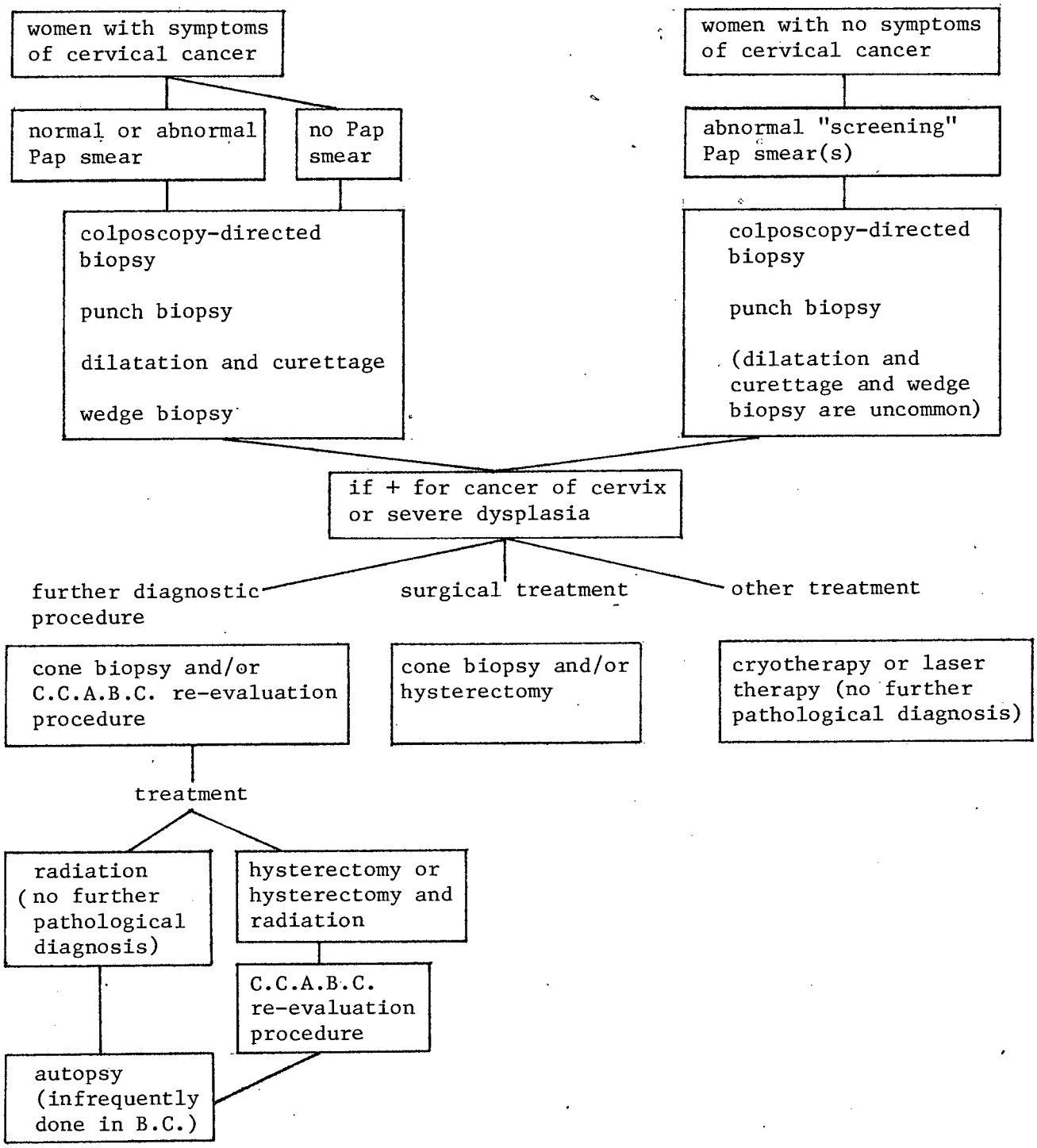
Table 4.1.1 - Pilot study of 57 cases, comparison of the Registry diagnosis with a best estimate (see text) of the true diagnosis. Classified by year and type of cervical cancer.

INVASIVE CERVICAL CANCERS (ICD-O CLASSIFICATION)		1977		1978		1979		TOTAL	
		Registry	Best Estimate Of Truth	Registry	Best Estimate Of Truth	Registry	Best Estimate Of Truth	Registry	Best Estimate Of Truth
Clinically invasive squamous cell carcinoma	8070/3	12	6	14	7	8	6	34	19
Micro or occult invasive squamous cell carcinoma	8070/4	3	7	2	2	3	3	8	12
Uncertain whether invasive squamous cell carcinoma	8070/8	-	-	-	-	3	-	3	-
Clinically invasive epithelial carcinoma	8010/3	-	-	2	-	-	-	2	-
Uncertain whether invasive epithelial carcinoma	8010/8	-	-	-	2	-	-	-	2
Clinically invasive undifferentiated epithelial carcinoma	8020/3	1	-	-	-	-	-	1	-
Uncertain whether invasive undifferentiated epithelial carcinoma	8020/8	-	-	-	-	1	-	1	-
Clinically invasive adenocarcinoma	8140/3	3	2	-	-	2	-	5	2
Uncertain whether invasive adenocarcinoma	8140/8	-	-	-	-	1	-	1	-
Clinically invasive papillary adenoma	8260/3	-	-	-	-	1	-	1	-
Clinically invasive clear cell adenocarcinoma	8310/3	-	-	1	1	-	-	1	1
Clinically invasive adenosquamous carcinoma	8560/3	-	-	-	1	-	-	-	1
	TOTAL	19	15	19	13	19	9	57	37

Table 4.1.2 - Pilot study, comparison of the Registry diagnosis by type of cervical cancer with a best estimate of the true diagnosis in the 20 cases that were incorrect.

INVASIVE CERVICAL CANCERS (ICD-O CLASSIFICATION)		Squamous cell cancer in situ (8070/2)	Adenocarcinoma in situ (8140/2)	Diagnosis made outside of B.C.	Primary site is not cervix	Duplicate registration	Total
Uncertain whether undifferentiated epithelial carcinoma	8020/8	1					1
Clinically invasive squamous carcinoma	8070/3	9		1		1	11
Uncertain whether invasive squamous carcinoma	8070/8	3					3
Clinically invasive adenocarcinoma	8140/3		1		2		3
Uncertain whether invasive adenocarcinoma	8140/8		1				1
Clinically invasive papillary adenoma	8260/3				1		1
	Total	13	2	1	3	1	20

Figure 4.1.1 - The recommended procedures of C.C.A.B.C. that lead to final pathological diagnosis of a cervical abnormality. This figure is a modified version of the one shown in a recent paper by Benedet, J. and Anderson, G. (1981).



diagnosis of invasive cancer for these 18 cases was based on the diagnosis on the first pathology report that the Registry received. However, the most valid diagnosis for each of these cases was made from subsequent specimens of tissue and/or from a pathologist's of the C.C.A.B.C. re-evaluation of the material used to make the first pathological diagnosis. This additional information was not entered into the Registry for 2 reasons. The first one was the Registry's routine procedure of recording all cases of cervical cancer as invasive unless the first pathology report specifically stated carcinoma in situ or dysplasia. This initial diagnosis of invasive cancer was never down-graded to non-invasive to reflect later information. This led to the inclusion of 15 cases of carcinoma in situ. The second reason was that the Registry did not receive the information from the C.C.A.B.C. re-evaluation procedure which changed the primary site diagnosis of 3 cases.

4.2 The Overall Results

Study of all cases for the years 1977-1979 gave similar results to the pilot study: 326 (63%) of the Registry's 521 recorded cases were confirmed pathologically as invasive cancer of the cervix (Table 4.2.1); 184 (35%) were reported incorrectly (Table 4.2.2); and for the remaining 11 (2%) of the 521 cases it was not possible to confirm or to refute the recorded diagnoses. Of the 184, 141 (77%) were actually pre-invasive cases, either in situ or with a lesser degree of dysplasia; 17 (9%) were invasive cancer of other sites; and 26 (14%) did not fit the criteria (outlined earlier) for an incident case. Ten of the 26 cases had an incorrect incident year, and in all cases the recorded incident year was at least 5 years in error with diagnosis having occurred in the 1960s or the early 1970s.

Finally, it was found when reviewing the cytology case files and clinical charts that 28 cases of clinically invasive squamous cell cancer of the cervix, diagnosed in 1977 to 1979 had not been included on the Registry's master list

Table 4.2.1 - Comparison of the Registry diagnosis with a best estimate of the true diagnosis. By year and type of cervical cancer for the total (521) cases registered in 1977-1979.

INVASIVE CERVICAL CANCERS (CATEGORIZED BY ICD-O SYSTEM)		1977		1978		1979		TOTAL	
		Registry	Best Estimate Of Truth	Registry	Best Estimate Of Truth	Registry	Best Estimate Of Truth	Registry	Best Estimate Of Truth
Unclassified invasive neoplasm	8000/3	1	-	1	-	5	2	7	2
Clinically invasive epithelial carcinoma	8010/3	9	-	10	-	8	-	27	0
Micro or occult invasive epithelial carcinoma	8010/4	5	2	5	-	3	1	13	3
Uncertain whether invasive epithelial carcinoma	8010/8	-	-	-	-	2	-	2	0
Clinically invasive undifferentiated epithelial carcinoma	8020/3	1	-	-	-	-	-	1	0
Uncertain whether invasive undifferentiated epithelial carcinoma	8020/8	-	-	-	-	1	-	1	0
Clinically invasive anaplastic epithelial carcinoma	8021/3	-	-	-	-	2	-	2	0
Clinically invasive papillary carcinoma	8050/3	-	-	1	-	1	-	2	0
Clinically invasive verrucous carcinoma	8051/3	-	-	-	-	1	-	1	0
Borderline malignancy squamous cell carcinoma	8070/1	-	-	-	-	3	-	3	0
Clinically invasive squamous cell carcinoma	8070/3	112	62	101	48	95	60	308	170
Micro or occult invasive squamous cell carcinoma	8070/4	18	29	25	42	29	30	72	101
Uncertain whether invasive squamous cell carcinoma	8070/8	-	-	-	-	20	-	20	0
Clinically invasive squamous cell (keratinizing type carcinoma)	8071/3	-	-	-	-	1	1	1	1

..... continued

Table 4.2.1 - continued

INVASIVE CERVICAL CANCERS (CATEGORIZED BY ICD-O SYSTEM)		1977		1978		1979		TOTAL	
		Registry	Best Estimate Of Truth	Registry	Best Estimate Of Truth	Registry	Best Estimate Of Truth	Registry	Best Estimate Of Truth
Clinically invasive squamous cell (large cell) carcinoma	8072/3	-	-	-	-	2	1	2	1
Clinically invasive basosquamous carcinoma	8094/3	1	1	-	-	-	-	1	1
Clinically invasive adenocarcinoma	8140/3	19	8	9	7	5	1	33	16
Micro or occult invasive adenocarcinoma	8140/4	-	3	-	-	-	1	0	4
Uncertain whether invasive adenocarcinoma	8140/8	-	-	-	-	1	-	1	0
Clinically invasive papillary adenoma	8260/3	-	-	1	-	3	1	4	1
Clinically invasive clear cell adenocarcinoma	8310/3	1	1	1	1	-	-	2	2
Clinically invasive mucinous adenocarcinoma	8480/3	-	-	1	-	-	-	1	0
Clinically invasive adenosquamous carcinoma	8560/3	4	7	5	7	2	3	11	17
Micro or occult invasive adenosquamous carcinoma	8560/4	-	-	-	-	1	3	1	3
Clinically invasive leiomyosarcoma	8890/3	1	1	-	-	1	1	2	2
Clinically invasive rhabdomyosarcoma	8900/3	1	1	-	-	-	-	1	1
Clinically invasive embryonal rhabdomyosarcoma	8910/3	1	1	-	-	-	-	1	1
Endometrial stromal sarcoma	8930/3	-	-	1	-	-	-	1	0
	TOTAL	174	116	161	105	186	105	521	326

Table 4.2.2 - Comparison of the Registry diagnosis by type of cervical cancer with a best estimate of the true diagnosis in the 184 cases that were incorrect.

INVASIVE CERVICAL CANCERS (CATEGORIZED BY ICD-O SYSTEM)		Carcinoma in situ, not otherwise specified (8010/2)	Papillary dysplasia (8050/0)	Squamous cell dysplasia (8070/0)	Squamous cell carcinoma in situ (8070/2)	Adenocarcinoma in situ (8140/2)	Adenosquamous carcinoma in situ (8560/2)	Diagnosis made outside of B.C.	Primary site not cervix	Duplicate registration	Incorrect year of diagnosis	Total
Unclassified invasive neoplasm	8000/3								3	2	1	6
Clinically invasive epithelial carcinoma	8010/3	2		2	3		1	1	2		5	16
Micro or occult invasive epithelial carcinoma	8010/4				3							3
Uncertain whether invasive epithelial carcinoma	8010/8			1	1							2
Uncertain whether invasive undifferentiated epithelial carcinoma	8020/8				1							1
Clinically invasive papillary carcinoma	8050/3		1	1								2
Borderline malignancy squamous cell carcinoma	8070/1				2				1			3
Clinically invasive squamous cell carcinoma	8070/3			6	86		1	5	3	7	3	111
Micro or occult invasive squamous cell carcinoma	8070/4				7				1			8
Uncertain whether invasive squamous cell carcinoma	8070/8				15							15
Clinically invasive squamous cell (large cell) carcinoma	8072/3				1							1
Clinically invasive adenocarcinoma	8140/3					4			2	1	1	8
Uncertain whether invasive adenocarcinoma	8140/8					1						1
Clinically invasive papillary adenoma	8260/3								2			2
Clinically invasive mucinous adenocarcinoma	8480/3					1						1
Clinically invasive adenosquamous carcinoma	8560/3						1		2			3
Endometrial stromal sarcoma	8930/3								1			1
	TOTAL	2	1	10	119	6	3	6	17	10	10	184

of all new cases of invasive cervical cancer diagnosed in B.C. between 1977 to 1979. Thus, there were errors of omission as well as commission.

4.3 The Reasons for Registry's Errors

The factors responsible for the 184 cases being reported incorrectly are presented in Table 4.3.1.

It can be seen that incomplete pathology information caused 130 (71%) of the Registry's errors. The 113 cases showing pre-invasive behaviour were diagnosed as such subsequent to the initial biopsy either by a cone biopsy, a hysterectomy, a dilatation and curettage, or the C.C.A.B.C. re-evaluation procedure. But as outlined in Section 4.1, the Registry's diagnosis of invasive cancer for these 113 cases was recorded from the first pathology report and remained unchanged. It originated from a colposcopically directed biopsy (see Appendix I) in 96% of cases. The diagnosis from this report was usually "cancer of the cervix" with or without the additional phrase "with an insufficient amount of tissue to assess for invasion." The Registry's usual procedure was to record such a case as an invasive cancer of the cervix and this diagnosis was not subsequently revised to reflect the diagnostic changes made by the further investigations before or during treatment. The 17 invasive cancers of the bowel or the endometrium or the ovaries were recorded as invasive cancers of the cervix and left unchanged because the Registry did not receive information on the most valid diagnosis for these cases. This information originated either from the C.C.A.B.C. re-evaluation of initial tissue specimen or an autopsy report.

Coding errors that were made while registering a new case accounted for 31 (17%) of the Registry's incorrectly reported diagnoses. The commonest mistake was the coding of a carcinoma in situ as an invasive rather than a pre-invasive cancer.

The poor quality of the information submitted to the Registry caused

Table 4.3.1 - The Registry's misreported cases of invasive cervical cancers by type of error and by cause.

Causal Factors	Type of Error					
	Pre-invasive lesions	Incorrect primary site	Incorrect incident year	Out of Province diagnosis	Duplicate registration	TOTAL
Incomplete pathology information on the case	113	17	-	-	-	130
Coding errors during registration of the case	28	-	1	-	2	31
Inaccurate information on the case sent to the Registry	-	-	-	6	8	14
Registration of the case by a death notification instead of a pathology report	-	-	9	-	-	9
TOTAL	141	17	10	6	10	184

the remaining 12% of the errors. Fourteen (7%) occurred because the case's name or the place of diagnosis on the pathology report that was used to register the case was inaccurate, resulting in either duplicate registrations or the registration of an out of province diagnosis. A further 9 (5%) arose because a death notification instead of a pathology report was used to register the case. On investigation, the 9 cases were not new cases of invasive cervical cancer. Each case had been diagnosed several years prior to death and was not registered at that time because the Registry had not received pathology reports for these cases.

The factor responsible for 28 cases of invasive squamous cell cancer of the cervix not being recorded by the Registry was incomplete notification of all positive cases. Thus, the pathology reports of these cases had not been sent by the C.C.A.B.C. cancer treatment centres or the pathology laboratories to the Registry.

4.4 Comparison of Information on Date of Death, or Fact of Death

As of May, 1981 the Registry's data indicate that 42 deaths had occurred among the 521 cases that were registered as being diagnosed with invasive cervical cancer in 1977, 1978 and 1979, while this evaluation uncovered 104 deaths by checking clinical charts. Moreover, when the Registry's misreported cases were excluded, the Registry's data indicated that only 25 deaths had occurred among the 326 cases of invasive cervical cancer, while this evaluation uncovered 85 deaths or over 3 times as many as the Registry's. This indicated that the Registry under-reported its case fatalities to a substantial degree.

Three reasons for this were discovered by reviewing the follow-up procedures previously described in Section 2.2 and by communicating with Registry staff. Three deaths had taken place outside B.C. and would have been excluded from the monthly lists of deaths in B.C. that had been compiled by the provincial Department of Vital Statistics and which had provided the

Registry with its information on case fatalities. In addition, it was often 2 to 6 months before a death was notified, via these lists, to the Registry. Thus, it is clear that as of May 1981 (the time when the Registry's information was generated for this evaluation), some of the 23 deaths which occurred among the cases in 1980 and 1981 would not yet have been reported to the Registry. Finally, the Registry was approximately one year behind in its manual follow-up procedure.

4.5 Comparison of Information on Marital Status, Age and Residence

As discussed in Chapter 3, part of the intent of this investigation was to compare the data on these three variables for all cases recorded by the Registry as being diagnosed with invasive cervical cancer in 1977, 1978 and 1979 with a "best estimate" of the "truth" obtained from the cases' clinical chart. In fact, it was only possible to examine 189 (58%) of the Registry's 326 pathologically confirmed cases. The other 137 (42%) were not treated at the Victoria or Vancouver cancer clinics so that clinical charts were not available from which to collect data on age, marital status, and residence, or they were treated at these two cancer clinics but their charts were for some reason not available for review.

As indicated in Table 4.5.1, for 94 (49%) of the 190 cases, marital status was not given on the pathology reports used to register the case. For the remaining 96 (51%) of the cases, 30 (31%) were coded as married instead of widowed or divorced or separated, because the Registry's source of information for this variable, a pathology report, only discriminated between single (Miss) or married (Mrs.).

For 185 (97%) of the 190 cases, the age recorded by the Registry appeared "true" to within one year. Total agreement was not to be expected because the Registry's data on age were recorded at the time of the first pathology report and clinical records showed age at the time of the case's admission to

Table 4.5.1 - Marital status recorded by the Registry compared with a best estimate of the true marital status.

Code	Registry		Best estimate of the true marital status	
	Absolute (N)	Relative (%)	Absolute (N)	Relative (%)
1. Single	5	2.6	12	6.3
2. Married	91	48.0	116	61.0
3. Widowed	0	0	39	20.5
4. Divorced	0	0	16	8.5
5. Separated	0	0	7	3.7
6. Unknown	94	49.4	0	0
	190	100.00	190	100.0

the cancer clinic.

For 57 (30%) of the 190 cases, the place of residence recorded by the Registry was incorrect. These errors occurred because the Registry recorded the residence of a case as the city where the first pathology report originated. Therefore, these 57 cases who all lived in outlying areas of northern B.C. or northern Vancouver Island but were referred to Vancouver or Victoria or Kamloops for the initial diagnostic procedure were coded as residents of these cities instead of their home towns.

CHAPTER 5: DISCUSSION AND CONCLUSION

This chapter is divided into three sections: (1) the quality of the Registry's pathological diagnoses; (2) the quality of the Registry's information on the factor date of death; and (3) the quality of the Registry's information on age, marital status and residence.

5.1 The Quality of the Registry's Recorded Pathological Diagnoses

5.1.1 The findings revealed that the Registry's reported number (521) of new cases of invasive cervical cancer, diagnosed in B.C. during the years of 1977, 1978 and 1979 was about 50% too high. One hundred and eighty-four (35%) of the 521 cases were not true cases of invasive cervical cancer. It was found that these errors arose because of problems with the methods of registration.

The major problem was the Registry's lack of a procedure to revise the first diagnosis recorded by the Registry so as to reflect the diagnostic changes occurring after initial registration. This problem is not unique to the B.C. Registry, as it has been documented in the literature for other registries (Ravinhar, B. et al 1975; WHO, 1976a; IARC and IACR, 1978). These works drew attention to the need of a cancer registry to establish procedures that collect and record all the pathological information generated during the routine diagnosis and treatment of registered cases. This was seen as the best means to ensure that a registry had recorded the best final diagnosis for each case.

The current investigation also indicated that the widespread use of colposcopy-directed biopsy in B.C. has increased the Registry's need for such a revising procedure. Since 1974 (Benedet, J.L. et al) it has usually been the first diagnostic procedure, performed on women with an abnormal pap smear(s) but without signs or symptoms of cervical cancer, in order to detect

cases of pre-invasive cervical cancer. The pathology report from the colposcopy biopsy is therefore the first report received by the Registry for these cases and its diagnosis is the one that is recorded by the Registry. However, frequently the tissue fragments from this type of biopsy are too small to allow a pathologist to diagnose the cervical cancer as invasive or pre-invasive (in situ). Another biopsy (e.g. cone) or hysterectomy is necessary to determine this.

In the present investigation, 108 (96%) of the 113 cases recorded by the Registry as invasive cervical cancer but found to be pre-invasive cases of cancer were registered from a pathology report that was generated from a colposcopy biopsy. For all these cases, a subsequent cone biopsy or surgical specimen revealed that the cancer was pre-invasive but this diagnostic finding was not entered into the Registry's masterfile because of its policy not to downgrade a diagnosis of invasive cervical cancer made at initial registration (as outlined earlier in Section 2.2.2). It is also evident that if the Registry decides to implement a revising procedure it should be done in conjunction with efforts to improve the notification rate of cases of cervical cancer, since in 50% of the pre-invasive cases that were recorded incorrectly as invasive the pathology reports from the treatment or investigations following the initial biopsy were not sent to the Registry.

A similar interpretation of the effect of colposcopy on the Registry's inaccurate reporting of invasive cervical cancer was given by Boyes et al (1981). They stated that the observed rise in the Registry's recorded number of new cases of invasive cervical cancer in the mid '70's was an artefact because it coincided with the introduction of the colposcopy directed biopsy on a large scale in B.C. They suggested that this reported increase was caused by the inclusion of cases of pre-invasive cancer and they supported this argument with findings from a review of all the cases reported by the

Registry as being diagnosed with invasive cervical cancer in 1975. They also justified this explanation by indicating that this type of misreporting by the Registry would not have occurred prior to the introduction of the colposcopy because the cone biopsy was the initial diagnostic procedure at that time. This type of biopsy usually produces sufficient tissue to allow a pathologist to accurately diagnose whether the cancer is invasive or in situ.

The other problems that caused the Registry to misreport cases were coding errors during the registration of the case and poor information received by the Registry. These same problems have been identified in other cancer registries (WHO, 1979; IARC and IARC, 1978; Barclay, 1975; Saxen, 1980). The commonest conclusion was that accuracy of recorded data can be improved by instituting ongoing quality control procedures that check the reliability of the information received and the consistency of coding practices.

An important implication of the Registry's inaccurate reporting of the number of new cases of invasive cervical cancer in 1977, 1978, and 1979 was that the recorded numbers, when used to calculate age standardized incidence rates, inflated these rates (Table 5.1.1 and Table 5.1.2). This was particularly true for the age group between 15-44. Overestimation in this group was high because of the inclusion of cases of pre-invasive cervical cancer. This type of error probably occurred predominantly in this age group and not in the others for several reasons such as: (1) the absolute frequency of pre-invasive lesions was maybe higher in younger women; (2) the relative frequency, that is, the proportion of all lesions that were pre-invasive was higher in younger women; (3) younger women were more likely to have had a Papánicolaou smear, increasing the likelihood of detecting pre-invasive lesions; and (4) younger women with abnormal Papanicolaou smears were more likely to have had a colposcopy rather than a cone biopsy or hysterectomy or dilatation and curettage.

Table 5.1.1 - Comparison of the Registry's age-standardized incidence rates with a best estimate of the true rates by year of diagnosis and by 5 year age groups, using world population as standard population. See Appendix III for the method of calculation of these age standardized rates.

AGE GROUP		1977	1978	1979
15 - 44	Registry's rates	14.11	14.95	16.96
	Best estimate of true rates	8.68	8.60	8.95
45 - 64	Registry's rates	24.77	16.97	20.44
	Best estimate of true rates	19.98	13.94	16.87
65+	Registry's rates	24.98	21.37	21.26
	Best estimate of true rates	18.48	19.52	13.48

Table 5.1.2 - Comparison of the Registry's age-standardized incidence rates with a best estimate of the true rates by year of diagnosis and by 5 year age groups, using Canadian population as standard population. See Appendix III for the method of calculation of these age standardized rates.

AGE GROUP		1977	1978	1979
15 - 44	Registry's rates	13.57	14.43	16.36
	Best estimate of true rates	8.07	8.30	8.39
45 - 64	Registry's rates	24.64	17.03	20.47
	Best estimate of true rates	19.99	13.99	17.08
65+	Registry's rates	23.00	21.50	21.54
	Best estimate of true rates	16.48	19.35	13.49

It is clear that the Registry's rates for these years should be used with caution by persons who are evaluating the effect of B.C.'s cytology screening programme on incidence trends or planning the number and type of facilities that are needed to treat cases of invasive cervical cancer.

Another implication of the present study is that the Registry may have over-reported the number of new cases of other types of cancers. This would have occurred most frequently in the case of cancers whose initial diagnosis generated from the first biopsy sometimes changes because of a subsequent pathological diagnosis established during the course of the disease (e.g. cancer of the colon). The Registry probably has not recorded the case's final diagnosis.

5.1.2 It was also found that the Registry's reported number (521) of new cases of invasive cervical cancer for the three years failed to include 28 "true" cases. It is possible that the true number of missed cases was higher than 28, since by the very nature of the problem it is impossible to be sure that all were detected. Because the Registry did not receive pathology reports for these cases this finding indicates a need to improve the notification procedures.

5.2 The Quality of the Registry's Information on Fact and Date of Death

The findings showed that the Registry did not report 71% of the deaths that occurred among the "true" cases of invasive cervical cancer diagnosed in B.C. during 1977, 1978, and 1979. This underreporting drew attention to the need to improve the method of linkage of death notifications (from the Provincial Division of Vital Statistics) with the Registry's master file.

In addition, the findings suggested that the Registry's data on the vital status of cases, if used to calculate survival rates, would have over-estimated these rates and would have provided poor data for evaluating treatment of invasive cervical cancer in B.C. It seems likely that the under-

reporting of deaths also occurs for other registrable cancers to a similar extent.

5.3 The Quality of the Registry's Information on Age, Marital Status, and Residence

The recorded data on the cases' age were usually correct but they were often inaccurate for marital status and residence. They showed that a pathology report (which was the Registry's source of information for these variables) often gave only age and sex, and gave very limited information on other demographic characteristics. Other sources of information - C.C.A.B.C. clinical chart or private physician - are, in fact, required to collect marital status and residence on most cases of invasive cervical cancer. In addition, these sources are able to provide data on a wider range of personal variables (religion, occupation, ethnic origin).

Thus, it was found that the Registry's information provided unreliable data for studies or reports that aim to classify new cases of invasive cervical cancer according to demographic features other than age and sex.

In conclusion, some of the information (diagnostic, death, and personal) on the cases of invasive cervical cancer recorded by the Registry as being diagnosed in 1977, 1978, and 1979 was inaccurate and incomplete. This occurred because of problems with the system of registration. The important implication of these findings is that the Registry has not been able to provide reliable data to health care professionals who wish to use it for a variety of purposes such as: monitoring the incidence of this disease over time; planning service facilities for invasive cervical cancer; and evaluating the provincial cervical screening programme. In addition, it may be implied that the problems with the Registry's methods of registration may have caused similar errors in the information recorded by the Registry for other types of cancers.

REFERENCES

Andrews, F., Lineham, J., and Melcher, D. "Cervical cancer in young women", Lancet, 2 (1978), 774-776.

Anglesio, E. "Problems in the initiation of a cancer registry", Recent Results in Cancer Research, 50 (1975), 20-25.

Antello, C. and Lao, C. "United States trends in mortality from cancer of the cervix", Lancet, 1 (1979), 1038-1042.

Barclay, T. "The evaluation of data collection procedures - assessment of completeness", Recent Results in Cancer Research, 50 (1975), 59-75.

Barnes, A., Payne, P., and Skeet, R. "The computerized registry", Recent Results in Cancer Research, 50 (1975), 26-32.

Benedet, J. and Anderson, G. "Cervical Intraepithelial Neoplasia in British Columbia: A Comprehensive Program for Detection, Diagnosis, and Treatment", Gynecological Oncology, 12 (1981), 280-291.

Beral, V. "Cancer of the cervix: a sexually transmitted infection?", Lancet, 1 (1974), 1040.

Berkley, A., Livolsi, V., and Schwartz, P. "Advanced squamous cell carcinoma of the cervix with recent normal papanicolaou tests", Lancet, 2 (1980), 375-376.

Berkowitz, R., Ehrmann, R., Lavizzo-Mourey, R., and Knapp, R. "Invasive cervical carcinoma in young women", Gynecologic Oncology, 8 (1979), 311-316.

Boyes, D., Worth, A., and Fidler, H. "Results of treatment of 4,389 cases of preclinical cervical squamous carcinoma", Journal of Obstetrics and Gynecology of the British Commonwealth, 77 (1970), 769-780.

Boyes, D., Worth, A. and Anderson, G. "Experience with Cervical Screening in British Columbia", Gynecological Oncology, 12 (1981), 143-155.

C.C.A.B.C. (Cancer Control Agency of B.C.) Cancer in B.C. 1978. Annual Report published in 1980.

Elwood, J.M. and Gallagher, R.P. "Surveillance systems for cancer and birth defects in relation to environmental and occupational hazards: the current situation and the need for progress." Report to the British Columbia Royal Commission of Inquiry into Uranium Mining in British Columbia, 1980.

Fidler, H., Boyes, D. and Worth, A. "The Cytology Programme in British Columbia", Canadian Medical Association Journal, 86 (1962), 823-830.

Fujimoto, I. and Hanai, A. "Cancer Registries in Japan", National Cancer Institute Monograph, 47 (1977), 7-15.

Gallagher, R. and Elwood, M. "Recent trends in the recorded incidence and mortality from uterine cancer", National Cancer Institute Monograph, 62 (1982).

Grace, M. and Davis, F. "Data adequacy, validity, reliability and accuracy", in Manual for Cancer Records Officers, ed. A.B. Miller. Ottawa: National Cancer Institute, 1975.

Green, G. "Rising cervical cancer mortality in young New Zealand women", New Zealand Medical Journal, 14 February 1979, 89-91.

Grundmann, E. "The pros and cons of cancer registration", Recent Results in Cancer Research, 50 (1975), 52-58.

Haenszel, W. "The United States network of Cancer Registries", Recent Results in Cancer Research, 50 (1975), 52-58.

IARC (International Agency for Research on Cancer) and IACR (International Association of Cancer Registries). Cancer Incidence in Five Continents, Volume III, Geneva, 1976.

IARC (International Agency for Research on Cancer) and IACR (International Association of Cancer Registries). Cancer Registration and its Techniques. Lyon, 1978.

Knowelden, J., Mork, T. and Phillips, A.J. The Registry in Cancer Control. Geneva: UICC Technical Report Series, 1970.

McBride, M. British Columbia Cancer Registry. Vancouver: C.C.A.B.C. document, 1981.

McGregor, J. and Tepu, S. "Cervical screening", Lancet, 1 (1974), 1401-1402 and 1221-1222.

NCI (National Cancer Institute). Manual for Cancer Records Officers. Ottawa, 1975.

Pedersen, E. "Some uses of the Cancer Registry in cancer control", British Journal of Preventive and Social Medicine, 16 (1962), 105-110.

Prendiville, W., Guilleband, J., Bamford, P., Beilby, J. et al. "Carcinoma of cervix with recent normal papanicolaou tests", Lancet, 2 (1980), 853-854.

Ravinhar, B. and Pompe-kirn, V. "Experiences of the Cancer Registry in Slovenia", Recent Results in Cancer Research, 50 (1975), 98-102.

Saxen, E. "Cancer Registry: aims, functions and quality control", Arch. Geschwulstforsch, 50 (1980), 588-597.

Staszewski, J. "Cancer registry data versus mortality statistics", Recent Results in Cancer Research, 50 (1975), 103-110.

Tuyns, A. "The collection of available information: possibilitites and limitations of international standardization", Recent Results in Cancer Research, 50 (1975), 14-19.

UICC (International Union Against Cancer). Cancer Incidence in Five Continents, Vol.I, Geneva, 1966.

Walton, R. et al. "The Walton Report", Canadian Medical Association Journal, 114 (1976), 2-32.

Waterhouse, J. "Strategies for the development of a coherent cancer statistics system", WHO Quarterly Stats, 33 (1980), 185-195.

WHO (World Health Organization). Cancer Statistics. Geneva: Technical Report Series 632, 1979.

WHO (World Health Organization), WHO Handbook for Standardized Cancer Registries. Geneva: WHO Offset Publication, 1976a.

WHO (World Health Organization), International Classification of Diseases for Oncology. Geneva, 1976b.

Yule, R. "Mortality from carcinoma of the cervix", Lancet, 1 (1978), 1031-1032.

APPENDIX I

GLOSSARY

GLOSSARY

Cancer Control Agency of B.C. (C.C.A.B.C.) re-evaluation procedure	- pathologists at the Cancer Control Agency re-examine all slides of cervical biopsies or tissue fragments that have been diagnosed as invasive (or probably invasive) by pathologists from general hospitals, prior to treatment. The diagnosis from this procedure is usually regarded as the most reliable final pathological diagnosis since autopsies on deceased cases of invasive cervical cancer are infrequently done in B.C.
Stages of cervical cancer:	
carcinoma in situ	- a pre-invasive cancerous lesion that is localized to the cervical epithelium. It shows no behavioural characteristics of malignant cancer such as invasion into surrounding connective tissue (stroma) or metastasis.
carcinoma in situ with microinvasion	- same as carcinoma in situ, however, some of the abnormal cells break through the basement membrane of cervical epithelium and infiltrate a short distance into the stroma (usually to a depth of less than 1 mm). It is believed that this represents the earliest stage of invasion.
occult-invasive carcinoma	- same as carcinoma in situ with microinvasion. However, the extent of stromal invasion is much larger. These patients are asymptomatic and a lesion is not seen on clinical inspection.
clinically invasive carcinoma	- a malignant cancer in which abnormal cells infiltrate or destroy the underlying stroma. This lesion produces clinical signs and symptoms of cervical cancer.
colposcopy-directed biopsy	- clinician visualizes the cervix microscopically by means of a colposcopy; localizes the zone(s) of cell atypia; and takes a single or multiple bite biopsy of the lesion.

cone biopsy	- the removal of a cone of tissue around the external os of the cervix. The apex of the cone extends up the endocervical canal.
cytology	- a microscopic examination of body cells as a means of detecting malignant changes.
dysplasia	- abnormal, sometimes premalignant, development of cervical cells.
hysterectomy	- a surgical removal of the uterus. It may be performed either abdominally or vaginally and is classified as radical, sub-total or total.
(i) radical	- total removal of the uterus, upper vagina, parametrium pelvic lymph nodes, fallopian tubes and ovaries. This procedure is only carried out for cancer.
(ii) total	- removal of the corpus and cervix uteri.
(iii) sub-total	- removal of the uterus at or above the level of the internal os of the cervix.
incidence	- the number of new cases of cancer that occur per population at risk in a particular geographic area within a defined time interval such as a year.
Papanicolaou test	- direct circumferential scrape of the cervix uteri. The material from this procedure is screened microscopically for abnormal cells.
pathology	- examination of tissue specimens removed for biopsy or during treatment or at autopsy, in order to diagnose cancer.
re-evaluation by C.C.A.B.C. pathologists	- see C.C.A.B.C. re-evaluation procedure pathologists.

APPENDIX II

THE ABSTRACT FORM USED IN THIS EVALUATION

IDENTIFICATION INFORMATION: (Not Computerized)

SURNAME: |_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|

GIVEN NAME(S): |_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|

PREVIOUS SURNAME: |_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|_|

REGISTRY NUMBER: |_|_|_|_|_|_|_|

CYTOLOGY IDENTIFICATION NUMBER: |_|_|_|_|_|_|_|_|

C.C.A.B.C. NUMBER: |_|_|_|_|_|_|

STUDY NUMBER: |_|_|_|_|_|

(continued)

REGISTRY INFORMATION:

STUDY NUMBER: [ ][ ][ ][ ][ ]

CARD NUMBER: [1]

MARITAL STATUS: [ ]

1 = single
2 = married
3 = widowed
4 = divorced
5 = separated
9 = unknown

ADDRESS: (B.C. School District codes) [ ][ ]

DATE OF BIRTH: D D M M Y Y [ ][ ][ ][ ][ ][ ]

PATHOLOGICAL DIAGNOSIS: (ICD-O code) [ ][ ][ ][ ][ ]

DATE OF DIAGNOSIS: M M Y Y [ ][ ][ ][ ]

DIAGNOSTIC METHOD: [ ]

2 = pathological
3 = autopsy
4 = cytological
5 = radiological
6 = clinical
9 = unknown

AGE AT DIAGNOSIS: [ ][ ]

SOURCE OF REPORT: [ ][ ]

00 = not stated
02 = death registration
03 = private physician
04 = Cancer Control Agency of British Columbia
05 = General Hospital
07 = Riverview Hospital
09 = Shaughnessy Hospital
10 = Ex-province
20-40 = pathology laboratories of specific hospitals in British Columbia

DATE OF DEATH: D D M M Y Y [ ][ ][ ][ ][ ][ ]

(continued)

CYTOLOGY PROGRAMME INFORMATION:

DATE OF BIRTH: D D M M Y Y

DATE OF DIAGNOSIS: D D M M Y Y

METHOD OF DIAGNOSIS: [ ][ ]

50 = bite biopsy
51 = multiple bite biopsy
52 = cone biopsy
60 = colposcopic direct biopsy
86 = hysterectomy tissue
53 = D and C tissue
74 = autopsy
99 = no record

SOURCE OF REPORT: (See source of report on page 42) [ ][ ]

PATHOLOGICAL DIAGNOSIS: [ ][ ]

01 = squamous dysplasia
02 = squamous carcinoma in situ
03 = squamous carcinoma
04 = invasive squamous carcinoma
05 = squamous carcinoma in situ with micro-invasive foci
06 = squamous carcinoma - occult invasive
07 = squamous carcinoma clinically invasive
08 = adenocarcinoma
10 = mixed
11 = other (specify) _____

C.C.A.B.C. RE-EVALUATION'S PATHOLOGICAL DIAGNOSIS* [ ][ ]

01 = squamous dysplasia
02 = squamous carcinoma in situ
03 = squamous carcinoma
04 = invasive squamous carcinoma
05 = squamous carcinoma in situ with micro-invasive foci
06 = squamous carcinoma - occult invasive
07 = squamous carcinoma clinically invasive
08 = adenocarcinoma
10 = mixed
11 - other (specify) _____

*These pathology diagnoses were converted into ICD-O code for the comparison of the Registry's diagnoses and the best estimate of true diagnosis.

(continued)

C.C.A.B.C. CLINICAL RECORDS:

AGE: [ ][ ]

ADDRESS: (B.C. School District codes) [ ][ ]

MARITAL STATUS: [ ]

1 = single
2 = married
3 = widowed
4 = divorced
5 = separated
9 = unknown

DATE OF DEATH:

D	D	M	M	Y	Y

APPENDIX III

THE METHOD OF CALCULATION OF THE REGISTRY'S ESTIMATE AND OF "THE BEST ESTIMATE" OF THE "TRUTH" AGE STANDARDIZED INCIDENCE RATES OF INVASIVE CERVICAL CANCER IN B.C.

APPENDIX III

Table 5.1.1

		World Standard Population (IARC)	Registry's + Crude Incidence Rates (per 100,000)	Registry's # Standardized Incidence Rates	"Best estimate" ## of Crude True Incidence Rates (per 100,000)	"Best estimate" # of True Standardized Incidence Rates
	15 - 44	43,000	13.83	14.11	8.23	8.68
1977	45 - 64	19,000	24.72	24.77	20.00	19.98
	65+	7,000	23.26	24.98	17.44	18.48
	15 - 44	43,000	14.64	14.95	8.68	8.60
1978	45 - 64	19,000	17.08	16.97	13.98	13.94
	65+	7,000	21.65	21.37	19.55	19.52
	15 - 44	43,000	15.07	16.96	8.61	8.95
1979	45 - 64	19,000	20.43	20.44	17.35	16.87
	65+	7,000	21.42	21.26	13.39	13.48

N.B. For footnotes +, # and ## see page 47.

Table 5.1.2

		Standard Population (Canadian population in 1976; in thousands)	Registry's + Crude Incidence Rates (per 100,000)	Registry's # Standardized Incidence Rates	"Best estimate" ## of Crude True Incidence Rates (per 100,000)	"Best estimate"# of True Standardized Incidence Rates
1977	15 - 44	5296.7	13.83	13.57	8.23	8.07
	45 - 64	2243.2	24.72	24.64	20.00	19.99
	65+	1126.9	23.26	23.00	17.44	16.48
1978	15 - 44	5296.7	14.64	14.43	8.68	8.30
	45 - 64	2243.2	17.08	17.03	13.98	13.99
	65+	1126.9	21.65	21.50	19.55	19.35
1979	15 - 44	5296.7	15.07	16.36	8.61	8.39
	45 - 64	2243.2	20.57	20.47	17.47	17.08
	65+	1126.9	21.27	21.54	12.28	13.49

N.B. For footnotes +, # and ## see page 47.

FOOTNOTES FROM PREVIOUS TWO PAGES

+ A crude rate, the numerator includes the number of new cases of invasive cervical cancer recorded by the Registry as being diagnosed in 1977 or 1978 or 1979. Federal census data was used to estimate the denominator.

The Registry's and the best estimate of true age specific incidence rates are adjusted by 5 year age groups to conform to IARC's world standard population and Canada's population in 1976.* This procedure reduces the effect of the age structure on B.C.'s population (higher proportion of older people compared to populations in other regions of North America) on the reported age specific incidence rates. It also facilitates comparisons of these rates among other populations.

The numerator includes all the new cases of invasive cervical cancer that were found in this evaluation and the 11 cases that were registered as being diagnosed with invasive cervical cancer, but could not be verified pathologically in this evaluation.

The federal census was again used to collect the numbers for the denominator.

* An example of the method of calculation of these rates for Registry's 1978 figures is shown below.

1978	15-19	20-24	25-29	30-34	35-39	40-44	Total
B.C. Population (in 1,000)	119.9	116.0	110.6	98.2	76.9	65.8	587.4
Number of new cases	2	10	16	24	10	24	86
Incidence rate per 100,000	1.66	8.62	14.46	24.43	13.00	36.47	14.64 (crude rate)
World Standard Population (proportion within 15 - 44 age group)	.20930	.18605	.18605	.13953	.13953	.13953	1.0
Contribution to age standardized incidence rate	.34744	1.60375	2.69028	3.40871	1.81389	5.08866	14.95273 (age standardized rate)