

THE UNIVERSITY OF CALGARY

Personal , Social and Health Care System Factors and
Stage of Disease at Diagnosis of Colorectal Cancer

by

Judith Mildred Birdsell

A THESIS

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DEGREE OF MASTER OF SCIENCE

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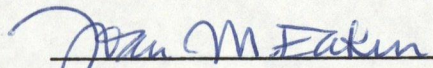
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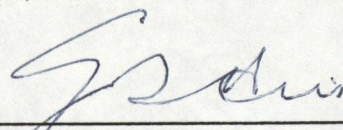
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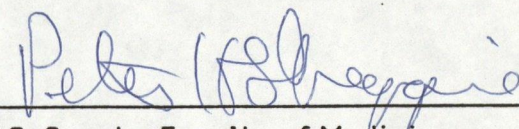
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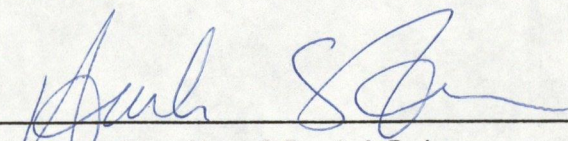
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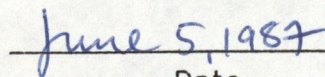
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ABSTRACT

Colorectal cancer is curable if detected early. In an effort to identify factors contributing to a late diagnosis of colorectal cancer, patients in Southern Alberta were interviewed to determine if early stage and late stage cases differed on any of six dimensions of an illness behaviour model. Forty seven males and thirty three females diagnosed in 1985 - 86 were interviewed in their homes. Information was collected on six areas from Cummings' Illness Behaviour Model; demographics, social network, attitudes toward health care, health care system variables (such as doctor visits), knowledge about cancer, and perceived health threat. Logistic regression was used to assess variables within each of the six areas and was then used to assess the full model including variables from all six areas. In the single area logistic regression factors which significantly contributed to predicting a late stage diagnosis (using remove and enter limits of .15 and .10, respectively) were attribution of symptoms to causes other than cancer; higher knowledge levels about Pap tests; lower knowledge level about Hemoccult tests; more visits to a general practitioner prior to diagnosis; more friends, neighbors, and ministers in their support network and a lower perceived level of tangible aid. In the full model logistic regression, the only two factors remaining in the model after adjusting for effects of the others were the tendency of late stage patients to attribute the cause of symptoms to something other than

cancer, and their increased number of visits to the general practitioner before being diagnosed. Of the six types of variables included in the model, demographic and attitudes toward health care did not seem to assist in explaining the difference between late and early stage colorectal cancer patients. A multiple causation model was an instructive approach to studying this problem, as the results of the full model multivariate regression were somewhat different than the single area analyses.

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DEDICATION

I would like to dedicate this thesis to my dad, Stewart Charles Birdsell, who died just as I was beginning my Masters' Program; and to whom education meant very little, and I meant a great deal.

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CHAPTER ONE: INTRODUCTION

This study is concerned, in a general sense, with reducing the mortality associated with colorectal cancer. Cancer is second to heart disease as the leading cause of death in Canada (Statistics Canada, 1984). Of the many different types of cancer known, colorectal cancer represents a significant threat. In Alberta, cancer of the colon and rectum is the second leading cause of death from cancer in women (after breast cancer) and the third most common cause of death from cancer in men (after prostate and lung). The incidence rates for colon and rectal cancer, respectively, in Alberta from 1979-1981 were 21.3 and 11.2 per 100,000 females and 19.0 and 14.1 per 100,000 males (Alberta Cancer Board, 1986). An individual born in Canada today has a 7% chance of developing colorectal cancer at some point in his/her lifetime. This compares to a 9.3% of getting breast cancer if you're a female, or a 6% chance of dying from suicide. (Canadian Cancer Society, 1987)

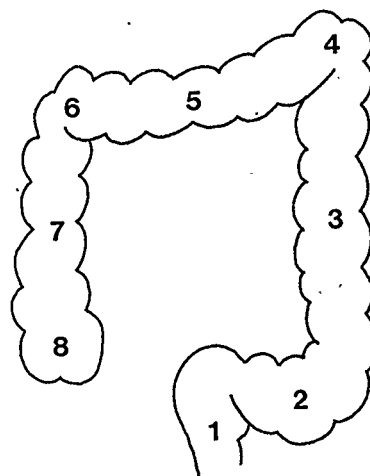
Risk factors for colorectal cancer include a history of ulcerative colitis or Crohn's disease; personal or family history of colorectal cancer; or personal history of polyposis coli or adenomatous polyps (Li, 1986). Although a small percent of patients are diagnosed incidentally without complaining of any symptoms, most patients go to the doctor with one or more symptoms, including abdominal pain, diarrhea, constipation, rectal bleeding, weight loss, appetite loss, nausea or

lassitude, for example. A diagnosis is most often made after a symptomatic patient goes to the physician and has a rectal examination, barium x-ray or a visual examination of the bowel using a scope or a combination of these procedures (Sugarbaker, 1986). Surgery to remove the primary tumour is the most common form of treatment. Eighty four percent of patients are treated surgically in Alberta. In recent years, chemotherapy and radiotherapy have been used in some cases, after surgery. In Alberta, 5 % of newly diagnosed colorectal cancer patients are treated by chemotherapy, 13 % are treated by radiotherapy, and 4 % receive both chemotherapy and radiotherapy, in addition to surgery (T. Snodgrass, Alberta Cancer Board, personal communication, 1987).

Malignant tumours are not distributed evenly along the rectum and large bowel, but rather tend to cluster in both ends of the large bowel. Figure 1 provides a schematic diagram of the distribution of colorectal tumors for the most recent three years in Alberta.

Figure 1: Distribution of Malignant Tumours in Colon and Rectum

1. Rectum (38%)
2. Sigmoid (19%)
3. Descending Colon (3%)
4. Splenic Flexure (2%)
5. Transverse Colon (6%)
6. Hepatic Flexure (3%)
7. Ascending Colon (7%)
8. Cecum (14%)



There is evidence, that for certain types of cancer, early detection and treatment lead to a better outcome than if these processes occur at a later stage. This is true for cancer of the colon, breast, melanoma, and cervix cancer (Levy, 1982). Suggestive evidence to support this statement is exhibited by survival rates such as those in Alberta. Actuarial four year survival rates for colorectal cancer patients in Alberta are 80% for early stage and 4% for the latest stage (Appendix I).

If prognosis improves with early detection and treatment, population screening for colorectal cancer becomes an issue. Although several studies are presently underway to assess the value of screening with occult blood tests for reducing mortality from colorectal cancer (Winawer et al, 1982; Hill et al, 1983; Hardcastle et al, 1984), the only screening method proven effective to date is a multiphasic screening program which included sigmoidoscopy (a direct visual examination of the lower bowel using a lighted scope) as one of the techniques (Dales, Friedman and Collen, 1979; Friedman, Collen, and Fireman, 1986). Population screening with sigmoidoscopy is not something which would be easy to recommend or implement. It requires special training for the endoscopist and involves a measure of discomfort and risk for the patient. Attempts have been made to develop techniques for doing selective screening for cancer, that is, to identify a subset of individuals who should be screened using techniques which, for one reason or another (expense, risk, difficulty)

are not suitable for population screening (Schechter et al, 1986; Soini and Hakama, 1978; Toti et al, 1980). Schechter and his colleagues (1986) showed that by including variables in their model which are not risk factors in the traditional sense, the ability of the model to select high risk cases for screening was increased. That is, not only etiological risk factors, but also factors such as social network factors, and the presence or absence of a family doctor are helpful in identifying people who would benefit more from being screened than would the general population. An editorial on the subject of selective screening pointed out that there may be some benefit in being able to describe profiles of patients presenting with late disease so that screening could be applied selectively to these populations (Hill, 1986).

Given that a late diagnosis is a distinct disadvantage in colorectal cancer, it is worthwhile to examine factors which may lead to a late diagnosis. The stage at which cancer is diagnosed may be influenced by a variety of factors. In a simplified model, these factors can be grouped into three main categories: 1) the inherent biological differences of tumors; 2) health care system factors which either facilitate or hinder an early diagnosis, and 3) patient factors which include such things as symptom perception and illness behaviours.

The purpose of the present study is to examine characteristics and experiences of patients which may differ between early stage colorectal cancer patients and late stage patients. These experiences include those which occur within the realm of family and friend

relationships, as well as those occurring during contacts with the health care system. Information gained from this study will contribute to the knowledge base necessary to facilitate early detection of colorectal cancer either through selective screening or the delivery of effective public education or professional education messages. Although very recent literature (Selby and Friedman, 1987) suggests that a discussion of selective screening may be premature, having the ability to identify persons at high risk for a late diagnosis would still provide valuable data on which to plan public and professional education messages.

Subsequent chapters include a review of the relevant literature, a description of the study as it was carried out, the results of the analysis, and a discussion of the results.

CHAPTER TWO. REVIEW OF THE LITERATURE

The purpose of this chapter is to review the literature in a fairly general way to select factors that may be theoretically or empirically associated with a late diagnosis of cancer. Three general areas for the literature review were identified: disease specific biologic factors, health care system factors, and factors describing patient behaviour. Factors describing the biology of the disease include such things as the nature and location of the tumour. Health care system factors include things such as the patient's access to health services, and the literature on patient behaviour includes mainly that related to illness behaviour (including help-seeking).

The critical outcome variable of interest for this study is stage of disease. There have not been very many studies done which examine the association between various explanatory factors and stage of disease. There have been many studies done, however, examining the relationships between explanatory variables and various other outcomes. Other outcomes which have been studied include help-seeking behaviour, patient delay in seeking care, delay by physicians in making a diagnosis, or survival. Therefore, literature involving outcomes other than stage of disease were included in the literature review.

Biologic Factors

Researchers have studied the ability of various tumour characteristics to predict outcome from colorectal cancer. These include histology, tumor size, location of the tumor, tumour markers, tumor adherence to adjacent organs and pathological stage (Wilson, 1986). Most colorectal tumors are adenocarcinoma and can be characterized by two histological characteristics; the tumor type (i.e. mucinous, colloid) and by the grade of the tumor (Wilson, 1986). Of all the microscopic characteristics of tumor histology, the one which is most helpful in predicting prognosis is tumor grade. As a general rule; the more undifferentiated the cells, the poorer the prognosis. The location of the tumor in the bowel also seems to effect prognosis somewhat. Evidence from a large multicentre study (National Surgical Adjuvant Breast Project) shows that the prognosis for tumors arising in the left colon was more favorable. Cancer of the right colon, rectum or rectosigmoid had significantly more recurrences (Wolmark et al, 1983).

Carcinoembryonic antigen (CEA) is the only established and useful marker for colorectal cancer (Wilson, 1986). A consensus conference in 1980 concluded that in colorectal cancer, serial monitoring of plasma concentration of CEA is the best technique for detecting recurrence. They also concluded, however, that the CEA blood assay was not sensitive enough nor specific enough to warrant use as a cancer

screening test (Go and Zamchuk, 1982) . In his review, Wilson (1986) concluded that tumor size and tumor adherence to adjacent organs were of little value in predicting outcome, but that pathological stage was the most important factor. Pathological stage definitions include the extension of tumor through the bowel wall, whether or not there is lymph node involvement and whether there is distant metastases.

Although biologic factors such as differentiation of tumour and location of primary are associated with ultimate survival, this knowledge is not helpful in planning for early detection, as these facts are available only after a diagnosis is made.

Health Care System Factors

Any patient who has had a pathologically diagnosed colorectal malignancy has had some contact with the health care system. It is the intent of this section to examine whether there are any factors or situations inherent in the health care system which may contribute to a late diagnosis. Health care system factors relevant to this discussion can be grouped into two main categories: physician characteristics and practices, and accessibility of health care .

Physician Characteristics and Practices

There is some evidence that physician attitudes and knowledge may contribute to the detection of colorectal cancer. In a Canadian study

done by Battista (1986) it was demonstrated that the most important determinant of whether doctors did preventive practice procedures (such as testing stool for occult blood in patients over 45) was the lack of perceived barriers by the physician. These perceived barriers included things such as physician lack of knowledge, low patient compliance, and time constraints. In Battista's study, if the above perceived barriers were absent (or the physician perceived only one) other factors were important in predicting preventive practice. Salaried physicians performed early detection tests more frequently than did fee for service physicians; female physicians did more tests than males, and those of both sexes who had undergone more continuing education did more early detection tests.

Other aspects of physician practice have been studied. Fowler et al (1984) studied two health care system variables (specialty of the physician making the diagnosis, and number of physicians seen from first visit until a tissue diagnosis was made) and their relationship to delay in diagnosis of cervical cancer. There was no association between stage of disease and specialty of the diagnosing physician. A delay (3 months or more from first visit to tumour diagnosis) was associated with seeing several physicians ("several" was not defined). This was an American study and further analysis from this study showed that patients covered under a health insurance scheme (Medicaid) saw more physicians than patients who paid for their care. These results suggest, as did Battista's (1986), that the manner in

which physicians were paid may have indirect effects on the stage of disease at diagnosis.

The practice of doing more preventive tests (as described by Battista, 1986) or of seeing more physicians (as described by Fowler et al, 1984) may influence the stage at which disease is diagnosed. It is not clear from Fowler's study, however, how much of the increase in number of physicians seen is associated with the fact that Medicaid patients saw more physicians than patients who paid for their care. This is relevant as late stage patients were significantly older in Fowler's study and Medicaid patients were also older. They did not do any multivariate analysis. It is not clear exactly which variables explain the increased number of visits by late stage patients.

The types of procedures physicians perform when providing care have also been associated with various outcomes indicative of prognosis. Vellacott et al (1987) in a comparison of 1974 and 1984 data, showed that there had been an increase in the proportion of colorectal tumours diagnosed in early stage over the 10 year period (36% of cases in 1974, compared with 53% in 1984). The authors attributed this change to routine use of double contrast barium enemas and more frequent use of colonoscopy and flexible sigmoidoscopy. In a British study of colorectal cancer, patients who were not given a rectal or abdominal examination on their first visit to the General Practitioner were found to experience more delay in being referred to a specialist (MacArthur and Smith, 1983).

There is some evidence that physicians may respond differently depending on the sex of the patient. In a study of sex differences in complaints and diagnoses, physicians rated neoplasms as more serious in men than in women (Verbrugge, 1980). When patients presented with digestive complaints, women were more likely than men to receive an "ill defined" diagnosis. Women with digestive complaints were also more likely to receive a urinary or genital diagnosis than men and this was especially true for abdominal pain. This evidence suggests that physician delay may be greater for women than men, although no one has reported on sex differences in physician delay.

Delay in diagnosis which can be attributed to physicians or other health care system factors is also a dimension of the health care system. This delay (called physician delay or Phase II delay by several authors) has proven to be more important in colorectal cancers than other types of cancer. Physician delay was found to be a contributing factor by MacArthur and Smith (1984) who found that the General Practitioner's failure to do a pertinent examination at the first visit was associated with delay in the patients' referral to a specialist. Holliday and Hardcastle (1979) found doctor delay to be particularly important in rectal cancer (as opposed to colon) with half of the patients being referred only after three or more patient visits.

In one of the above studies (MacArthur and Smith, 1984) delay was significantly associated with stage of tumour at diagnosis, but Holliday and Hardcastle (1979) did not report directly on the

association of stage with delay. They did report that there was no association between stage of disease and duration of symptoms. Duration of symptoms would presumably be equivalent to that delay which is patient related, but not necessarily to delay associated with the physicians.

Physicians are an integral part of the health care system, and it seems as though their practices may influence stage of disease at diagnosis. The other major aspect of the health care system relevant to this review is the area of availability of health care services for patients. This topic is often called "access" in the literature.

Accessibility of Health Care Services

Mechanic (1983) identified access to health care as one factor which may have an important bearing on help seeking and health care utilization. He identified several factors as being potential barriers to access. These factors included geographic location, cost, bureaucratic responses, social distance between patient and doctor, lack of a regular and continuing relationship with an appropriate professional and stigma which may be perceived when one seeks assistance.

In a panel study where people were followed every six weeks for a year with regards to symptoms and help-seeking, it was found that a regular source of medical care was significantly related to use of physician services (Berkanovic, Telesky, and Reeder, 1981). In a study that characterized people who failed to comply with a directive from a

cancer screening centre to seek medical attention, it was found that failing to identify a family doctor on the intake form was the most important determinant of noncompliance, followed closely by no recent visit to the doctor (Greenwald, Becker, and Nevitt, 1978).

Although there has not been a tremendous amount of research reported that looks specifically at the relationship between access and outcome from cancer, it seems as though access to health care and the behaviour of physicians once contact is initiated could potentially influence stage of disease at diagnosis.

Factors Influencing Patient Behaviour

A wide variety of factors have the potential to influence the behavior of an individual faced with illness. These factors include, but are not limited to, perception of threat to one's health, knowledge about the disease, attitudes to health care, sociodemographic factors such as age, sex, income, religion, and education as well as the influence of one's social network. Help-seeking behaviour (including "delay") is often the dependent variable in studies which examine the effects of the above variables.

Perception of Health Threat

This group of variables refer to the process whereby a person

identifies symptoms, assesses the significance of those symptoms, and makes a decision on the type of help, if any, to seek (Mechanic, 1983; Cummings, Becker and Maile, 1980). There seem to be two major dimensions to the health threat variable. The first has to do with the "objective" aspects, although it is recognized that symptom experience can never be truly objective because it is unique to the individual. Nevertheless, the objective aspects include things such as what the symptom was, how long it had been present, and whether it was severe or mild. The "subjective" aspects of health threat refers to how the person interpreted the symptoms. This would include such things as fear of suspected disease, perception of how much symptoms interfered with daily activities, and feelings of distress and discomfort arising from the identification of symptoms (Cummings et al, 1980).

The "objective" aspect of symptoms experienced by colorectal cancer patients has been reported by several authors (Bassett, Bennett and Goulston, 1979; MacArthur and Smith, 1984; Vellacott et al ,1987; Pitluk and Poticha, 1983; Miller and Leichty, 1967). Table 1 gives a summary of the most common symptoms in colorectal cancer as identified in several studies. In four studies which included all stages of colorectal cancer, abdominal pain was the most frequent symptom experienced. Bleeding and changes in bowel habits (either diarrhea or constipation) were the second most frequently reported symptom.

Table 1. Type and Frequency of Most Common Symptom

Reference	Most Frequent Symptom	% Experiencing	Source of Data
Bassett et al, 1979	Abdominal pain	58	Patient chart
Vellacott et al, 1987	Rectal bleeding	Not stated	Chart (Dukes A only)
MacArthur and Smith 1984	Abdominal pain	52	Patient interview.
Miller and Liechty 1967	Abdominal pain	61	Chart
Pitluk and Poticha 1983	Abdominal pain	58	Chart

Winawer (1983) suggested that early stage patients are largely asymptomatic. It seems that the nature of presenting symptoms has implications for health actions by the patient. In MacArthur and Smith's study (1984) patients experiencing abdominal pain or nausea and vomiting went most quickly to the doctor.

Not only is the specific type of symptom a factor in how one interprets the symptom, but also the duration, frequency and severity of the symptom may be important. There does not seem to be a clear and consistent relationship between the duration of symptoms and

extent of disease at diagnosis. In Bassett, Bennett and Goulston's (1979) study of colorectal cancer there was a negative correlation between duration of symptoms and extent of spread. Patients with localized tumor had had symptoms on average for 10.6 months, compared to 6.6 months for late stage. Those authors suggested the biological behaviour of the tumor was the determining factor in prognosis, rather than duration of symptoms. Several authors have found no relationship between duration of symptoms and Dukes stage (Holliday and Hardcastle, 1979; Dent, Chapuis, and Goulston, 1983; Irvin and Greaney, 1977; Chapuis et al, 1985). One study showed that patients with symptoms present for less than three months had a significantly shorter survival than patients whose symptoms had been present longer (McDermott et al, 1981).

Not only the objective aspects of symptoms, but also the subjective aspects, that is, how the patient interprets them, have consequences for action. In one study, if individuals perceived their cancer relevant symptoms as serious, they were more apt to go to the doctor (Berkanovic, 1982). A couple of investigators studying the reaction of cancer patients to their symptoms, have asked patients (after a cancer diagnosis) to what they attributed their symptoms when they first experienced them. Smith and Anderson (1987) studied women with endometrial cancer and found that less than 10% of women thought their symptoms were due to cancer. Most felt they were due to relatively benign conditions (menstrual conditions and other unknown

causes) However, there was a suggestion ($p=.10$) that earlier stage patients were more apt to think that their symptoms were due to cancer.

Hackett, Cassem and Raker (1973) studying several cancer sites, found something similar to Smith and Anderson (1987). They asked the patient "What is the name of your condition?" The patients who labelled their condition "cancer" sought help significantly faster than those who called it a tumor or something else. On a site by site comparison though, colon cancer patients were less apt to call their disease cancer. Seven percent of colon cancer patients said they had cancer, compared with 56% of breast cancer patients. In another study 90.5% of colorectal cancer patients stated that they had not considered cancer as a possible cause of their symptoms compared with 50% of breast cancer patients (McArthur and Smith, 1984).

There seems to be a suggestion from the literature that the objective aspects of symptoms are not related to stage of disease at diagnosis. At least, longer duration of symptoms is not associated with a late diagnosis. Conversely, the "subjective" aspects of perception of symptoms might be related. None of the studies reported however, looked at this perception specifically for colorectal cancer.

Knowledge

Knowledge is often assumed to be an important component of the

process leading to better health, and there have been many studies examining the relationship between knowledge, attitudes and the practice of a particular lifestyle element (For review, see Norman, 1986). There have been relatively few studies though, which have examined the relationship between knowledge and outcome from a specific illness. Knowledge of services and/or of disease is included as a component of several illness behaviour models (Cummings, Becker and Maile, 1980). In the simplest sense, it is obvious that to use a certain type of service, one must be aware of its existence; however, mere knowledge of the existence of a service does not guarantee appropriate usage. When knowledge has been studied in the past, it has often been in the context of health services utilization as the outcome.

Green and Roberts (1974), in their very extensive review of the literature on why women delay in seeking medical care for breast symptoms, included knowledge about the disease as one of the relevant factors. It was obvious that the data and definitions they were using to assess "knowledge" varied a great deal. Their conclusion was that there was no clear, direct relationship between knowledge, in a general sense, and taking action to seek care for their symptoms. Antonovsky and Hartman (1974) in another review article also concluded that there was no conclusive evidence that "ignorance of the existence of cancer diagnosis or screening facilities makes any major contribution to delay and to failure to participate in screening programs". Green and Roberts (1974) did, however, single out specific components of the knowledge

factors for which they did feel there was evidence of a relationship. They felt that knowledge of the significance of symptoms was consistently associated with decreased delay. There was evidence, though, that this was not a simple, linear relationship, and that, when knowledge level interacts with other factors, particularly fear of cancer, the help seeking behaviour may vary. Knowledge of symptoms combined with high fear level tended to increase delay, whereas if the fear level was low, knowledge decreased delay.

In a more recent study, DiClemente and Temoshek (1984) found that among melanoma patients, delayers (more than 3 months from first symptoms to first doctor visit) had substantially less previous knowledge of melanoma. This study also confirmed the concept of knowledge as defined in earlier studies (knowledge of symptoms and seriousness of same) because "delayers" stated that they waited to consult a physician because they "thought the condition was not serious". This study was important because they also examined the relationship between delay and pathological extent of disease at diagnosis. (DiClemente and Temoshek, 1984)

Attitude toward Health Care

Attitudes toward health care are felt to be important because in a general sense, they can either promote or inhibit utilization of health care service (Hulka et al, 1975). In a review of illness behaviour

models, examples of attitudinal variables were satisfaction with health care received in the past, perceived benefits of health actions, assessment of treatment plans, and beliefs concerning the value of physicians and health services. (Cummings, Becker and Maile, 1980)

The perceived benefit of health action is an integral part of the Health Belief Model (Becker, 1974) which has been used extensively to try to explain many health actions, but particularly those to do with preventive health actions (Janz and Becker, 1984). Perceived benefit of a particular action was significant in 78% of the studies reported which used the Health Belief Model (Janz and Becker, 1984).

In a study of help seeking behaviour related to cancer relevant symptoms, the belief that the doctor could be of some help in alleviating the symptoms explained more of the variance in the decision to seek help than any other variable (Berkanovic, 1982). Several investigators have worked on developing valid and reliable scales to measure an overall attitude toward the health care system (Ware and Snyder, 1975; Zyzanski et al, 1974). More recently, researchers have developed scales that measure attitude based on a particular doctor patient interaction (Wolf et al, 1978; Feletti et al, 1986). Hulka and her colleagues (1970) developed, tested and subsequently modified a scale which measures three distinct conceptual areas; professional competence, personal qualities of the physician and the cost and convenience of care. (Zyzanski et al, 1974)

Hulka's scale was used to assess the level of satisfaction with

medical care in a community of 200,000 people (Hulka et al, 1975). Men were less satisfied than women, in general. There was a high degree of correlation between attending the same physician for a long time and positive attitudes. They did not report, nor did any other report located, on satisfaction with medical care and outcome from cancer. However, there is indirect evidence that satisfaction may potentially be associated with intermediary variables (i.e. help-seeking). In Hulka's study (1975) women without a regular source of care had the lowest satisfaction scores. In other studies, lack of a family physician has been associated with delay in seeking medical care, for example. (Greenwald, Becker and Nevitt, 1978)

Demographic Variables

Sex, age, education and socioeconomic status are factors frequently assessed in health care research in conjunction with a wide range of dependent variables or outcomes. It is well known that low socioeconomic status is associated with higher mortality, morbidity and disability rates across a wide variety of diseases and conditions. (Norman, 1985) In a review article on delay, Antonovsky and Hartman (1974) felt that socioeconomic status was one of the two variables (age being the other) that predicted delay in seeking care for cancer. Although age was considered to be a predictor of delay in the above article , it is not clear that age is consistently a predictor of health or

illness behaviour. Norman points out that in cross sectional studies, behaviour does indeed seem to vary with age, but in two longitudinal or cohort studies that have been done (Mechanic, 1979; and Breslow and Enstrom, 1980) individuals' health behavior seemed to remain fairly constant over time.

It is also well known that there are many apparent differences between the sexes and various outcomes in the health/illness literature. It is not clear whether these differences are inherently gender related or whether sex is a marker for other factors, which indeed differ. Verbrugge (1985) reviewed the current status of the literature on gender and physical health. Statistics consistently show higher mortality rates for men but higher morbidity and health services utilization rates for women (Verbrugge, 1985).

Marshall, Gregorio and Walsh (1982) hypothesized, that since women tend to be more informed about symptoms of serious disease and visit physicians more frequently than males, that women should be diagnosed at earlier stages of disease. They did not find this to be the case. In their series, women had significantly more advanced stages of colorectal cancer than men. For both colon and rectal cancer in their study, the mean reported delay from first notice of symptoms to diagnosis was longer for females.

Social Network Variables

The influence of one's immediate social environment is another variable examined for its' potential influence on patient behaviour. There have been numerous studies done in the past ten years examining the relationship between social support and health and in a recent article, Broadhead and others (1983) reviewed the evidence for a causal relationship between social support and health. It is probably fair to say that there is a causal role for social support but the relationship is far from defined.

Several authors have suggested mechanisms whereby social support could be related to health outcomes . Hammer (1983) discussed four hypotheses of the relationship of social support to health and illness. They are:

1. Illness leads to reduced social contact and hence lowered social support.
2. Social networks affect health by mediating health related activities.
3. Social networks buffer the negative effects of stress on health.
4. Social feedback maintains or distorts social behaviour, with physiological consequences.

The last three hypotheses, unlike the first, view social support as being causally related to illness.

As social support is a relatively recent concept within the health

care literature, research about its effects is somewhat confused by the lack of consensus on definitions and scope. Many researchers have considered social support (see, for example, Flaherty et al, 1983; Norbeck et al, 1981; Cassel, 1976; Sarason et al, 1983; Schaefer et al, 1981; Hammer, 1983; Berkman and Syme, 1979; House et al, 1982; Gore, 1978; Broadhead et al, 1983; Asher, 1984) and generally speaking, social support is thought of as having two dimensions, one of quantity and one of quality. These two dimensions have taken different forms in different studies and some researchers have looked at only one of them. Berkman and Syme (1979), for example, whose Social Network Index proved useful in predicting all cause mortality as well as cancer mortality, included only "quantity" aspects of social relationships, and they did not attempt to measure the individuals perception of how adequate those social contacts were (Berkman and Breslow, 1983). The social contacts included in their index were marital status, an index of friends and relatives, church group membership and membership in other groups. Procidano and Heller (1983), on the other hand, focused on the quality aspect of social support, when they measured level of perceived social support from friends and family.

Thoits (1982) has presented some useful definitions for use when studying social support that seem to encompass the salient parameters discussed by many others. She defines the social support system as "the subset of persons in the individuals' total social network upon whom he or she relies for socioemotional aid (e.g.

affection, sympathy and understanding, acceptance, esteem), instrumental aid (e.g. advice, information, help with family or work responsibilities), or both. Social support systems can then be viewed as having two dimensions, structural and functional. These two dimensions correspond roughly to those of quantity and quality mentioned earlier. Structural properties of networks include such things as size, density, (degree to which network members know each other) accessibility, kinship, frequency of contact, etc. (Fisher,1977; Thoits,1982) Functional properties of social support include the perceived amount and adequacy of aid received from the identified support system members (Thoits, 1982).

The hypothesis as discussed by Hammer (1983) that social networks affect health by mediating health related activities has been tested in several studies. A longitudinal study done in Los Angeles examined factors which were related to the decision to seek care for cancer relevant symptoms (Berkanovic, 1982). Sixty percent of the variance in the decision to seek medical care for the cancer symptoms was explained by nineteen variables. Forty one percent of the variance was accounted for by social network influence and personal beliefs about the particular symptom. Network advice to see a doctor was an important variable and the only two items which explained more of the variance were perceived seriousness of the symptom and perceived efficacy of care. Patients who were physically close to their family and friends and who discussed their symptoms with them, and were

advised by their network to see a doctor for a particular symptom were more apt to do so. The social network information was collected specifically with regard to the particular symptom in question. Advice from family and friends was also an important variable in reduced delay in seeking treatment for colorectal cancer (MacArthur and Smith, 1984). Personal advice to go to the doctor reduced delay, and it did not matter whether the advice came from spouse, parent, child or friend.

In other studies, there has been a suggestion that different structural characteristics of support networks have different implications for health related activities. Birkel and Reppucci (1983) found that the frequency with which clients asked for advice and information from professionals about child rearing was negatively related to the density of the social network and the frequency of contact with family. In their study, highly dense, kin dominated networks apparently served as alternate providers of information and advice and discouraged help seeking from professional sources. Salloway and Dillon (1973) studied utilization of services and selected aspects of family and friend networks. They found that individuals with friend oriented networks experienced less delay in utilization of health services during specific illness episodes than those individuals who had more kin oriented networks.

The hypothesis that social support buffers stress related disease has received a moderate amount of attention in the research literature (Nuckolls et al, 1972; Gore, 1978), as well as a degree of criticism

(Thoits, 1982). The buffering hypothesis is more suited to examination of the role of social support in the etiology of disease. The present study is not concerned with the etiology of colorectal cancer, but rather with factors which influence the stage at which a diagnosis is made and treatment begun. Therefore, for the purposes of the present study, social support is viewed as a possible influence on health related activities. (i.e. help - seeking).

Critique of Existing Literature

Choice of Dependent Variable

The intent of early detection of cancer is to reduce the patient's chance of dying from the disease. There seems to be general consensus that pathological stage of disease at diagnosis is the best predictor of outcome. Yet, in most of the numerous studies that have examined behavioral aspects of cancer patients with a view to reducing mortality, the dependent variable has almost always been delay, or lagtime from some relevant event (usually first symptom) to some other relevant event (usually first doctor visit, or diagnosis).

If there was an indisputable link between "delay" and ultimate outcome from cancer, or between "delay" and stage of disease at diagnosis, "delay" would be a reasonable outcome or dependent variable. However, there is no clear and well established link between delay and stage of disease at diagnosis. Many investigators have not

even reported on the relationship between delay and stage, and in those studies where they have, the findings have been equivocal.

Temoshak et al (1984), in one of the few studies that considered a pathological definition as a dependent variable, did show that as far as malignant melanoma goes, delay was associated with pathologically more advanced tumours. Elwood and Moorehead (1980) demonstrated from a chart review of 1591 breast cancer patients, that shorter delay time was associated with longer survival. In their study of colorectal cancer patients, MacArthur and Smith (1984) showed that overall delay (time from onset of first symptom to definitive treatment) was significantly related to degree of spread of the tumour.

On the other hand, there have been studies that have reported no association between delay and pathological stage of colorectal cancer (Holliday and Hardcastle, 1979; Irvin and Greaney, 1977).

The use of stage of disease at diagnosis as the dependent variable in studies such as these, seems to make more sense. Delay may be one factor contributing to a poor prognosis, but it is obviously not the only one. The nature of initial symptoms and their interpretation by the person will influence help-seeking. If an individual does not perceive a problem, then delay is not an issue. Also, factors inherent in the health care system, such as availability of appropriate specialists, or lack of evening clinic hours, could intervene to increase the time period before a diagnosis is made, and again, delay on the patient's part may not be the most relevant variable.

Design and Analysis Issues

Another limitation of studies done to date is the the type of analysis done. DiClemente and Temoshek (1984) in a review of design weaknesses of delay studies, identified the lack of multivariate analysis as a weakness in most of the studies. MacArthur and Smith (1984) who used patient interview data and have published the most recent report, did not do multivariate analysis. Berkanovic (1982) did use multivariate analysis when he examined factors that led to the decision to seek care for cancer relevant symptoms, but there is no evidence that the decision to seek care is directly related to stage of disease at diagnosis. The decision to seek care may be related to stage of disease at diagnosis, but it is possible that other health care system factors may intervene between help-seeking and a definitive diagnosis.

Although there have been many studies reported with indirect relevance to the early detection of colorectal cancer, relatively few have studied colorectal cancer specifically. The most recent study reporting on factors influencing delay of diagnosis of colorectal cancer, did report on the association of delay with stage of disease. They did not, however, do multivariate analysis , and as previously mentioned this has been identified as a major weakness of studies done to date (DiClemente and Temoshek, 1984). Given these limitations, it seems that what is needed is a study analyzed using multivariate statistical techniques which investigates multiple factors as possible predictors of a late stage diagnosis of colorectal cancer.

Models of Illness Behaviour

Studies which attempt to explain why people behave as they do when faced with an illness invariably use a multifactor approach. Regardless of whether the outcome of interest is delay in seeking health care, utilization of health services, help seeking behaviour or others, there is considerable overlap in the types of variables that are included in an attempt to explain the particular outcome. They include factors related to the health care system, such as availability of services, and physician behaviour; and factors related to the individual, such as knowledge of disease, perception and interpretation of symptoms, help seeking behaviour, and influence of salient factors in one's environment i.e. family and friends. There have been many models used to try to explain why people take the actions they do when they interact with the health care system. (Suchman, 1965; Fabrega, 1973; Anderson and Bartkus, 1973; Antonovsky and Kats, 1970; Langlie, 1977)

Cummings and his colleagues (1980) attempted to reduce the ideas and concepts inherent in all the previous models into one comprehensive model. They did this by inviting several of the original authors of the models cited above to serve as judges in evaluating all of the individual variables. There were a total of 109 variables extracted from the models and the expert judges were asked to group

similar variables together. This model-synthesizing exercise resulted in a fairly concise model with six distinct categories which included virtually all of the original variables. The authors discovered that many of the individual variables in the separate models were measuring very similar concepts; the models were far from independent. The resulting model (Cummings Illness Behaviour Model) provides a fairly complete representation of factors thought by experts and originators of the model to influence health actions. The six major categories of variables that emerged were:

1. Accessibility of health services;
2. Attitudes toward health care;
3. Threat of illness, such as the individual's perception of symptoms and beliefs about susceptibility to and consequences of disease;
4. Knowledge about disease;
5. Social environment within which the person functions, and
6. Demographic factors.

Because these categories had been derived from several comprehensive models and represented a "consensus" of experts, so to speak; and because they seemed to include many of the factors which may be related to enhanced chances of an early diagnosis of cancer, a decision was made in the present study to examine differences in the outcome of interest (early versus late diagnosis of cancer) vis a vis Cummings Illness Behaviour Model. The first category (access) was expanded to include health care system factors generally, and not only

access to health care.

The Present Study

Weaknesses identified from the literature review include:

1. Many studies reported have been done using chart reviews, with all the attendant problems of using records that are being used for a secondary purpose, after the fact.
2. Lack of multivariate analysis.
3. Use of delay as a dependent variable, rather than stage of disease, which has been clearly established as important as far as prognosis goes.
4. Lack of studies which look specifically at colorectal cancer.

This study, therefore, has as its' outcome of interest the stage of disease at diagnosis of colorectal cancer. Pathological stage is the best predictor of ultimate outcome from colorectal cancer (Chapuis et al, 1985; Wilson, 1986; Hardcastle and Armitage, 1984). Therefore, using the multivariate Cummings model to examine differences between patients with a good prognosis (early stage) and those with a poor prognosis (late stage) the research questions of this study are:

1. Are social factors related to stage of disease at diagnosis?
2. Are demographic factors related to stage of disease at

diagnosis?

3. Are health care system factors related to stage of disease at diagnosis?
4. Are attitudes to health care related to stage of disease at diagnosis?
5. Is knowledge related to stage of disease at diagnosis?
6. Is the nature of the health threat posed by the symptoms related to stage of disease at diagnosis?
7. In a multivariate model, can the difference between late stage patients and early stage patients be described by any or a combination of the above variables?

CHAPTER 3: DESCRIPTION OF STUDY METHODS

This is an analytical study which examines differences between two groups of colorectal patients. The two groups are differentiated by stage of disease at diagnosis (early versus late) and they are examined from the perspective of an illness behaviour model. Information was collected in an interview with the patient and included data about the events and perceptions leading up to a diagnosis of colorectal cancer.

The Sample

Sampling Frame

The study was carried out in Southern Alberta. The sampling frame consisted of all colorectal cancer patients diagnosed between October, 1985 and August, 1986 and registered at the Tom Baker Cancer Centre (TBCC) in Calgary.

Criteria for Eligibility

1. The patient had a pathologically confirmed malignancy of colon or rectum.
2. Patient was officially registered by the attending physician with the Cancer Board within 3 months of diagnosis . This was necessary so that the patient's address was known.
3. Patient lived within one and a half hours drive from Calgary or

was coming to the Tom Baker Cancer Centre (TBCC) for radiation treatment.

Sample Size Calculation

A sample size of 40 in each group (early stage, late stage) was chosen after doing sample size calculations using the methods described by Rosner (1982). Using social support as the variable of interest, the sample size was calculated using mean social support scores as described by Lin (1979) and by using data on marital status from the Cancer Registry as a proxy for social support. A sample size of 28 was required to measure an increase in social support scale of 3 points (from 23.5 to 26.5) at 80% power and significance level of .05 (one tailed test). Using Cancer Registry data on marital status (.59 of early colorectal cancer patients were married) a sample size of 51 was required to detect a Relative Risk of 3.0 for the association between not being married and having a late stage diagnosis.

Data Collection

Overview

A chronological description of study procedures follows:

1. Patients were identified from the Cancer Registry and from lists of other pathologically confirmed cases not yet registered. These lists of confirmed cases were kept for the purposes of identifying patients potentially eligible for clinical trials.

2. If the patient identified in Step 1 was officially registered by the attending physician within 3 months of diagnosis, a letter was sent to the physician, describing the study and requesting contact with the patient. The physician was asked to call the author if he/she felt that his patient should not be contacted.

3. If no objection was received within two weeks after the doctor's letter was sent, a letter was sent to patients informing them that they would be called in a few days to ask if they would agree to be in the study. An information sheet was included which explained the study and provided a phone number to call for more information.

(Appendix II) A small number of patients who were coming to the TBCC for treatment or consultation were approached and given the letter initially in the outpatients department at the Centre.

4. If, on being phoned several days after the letter was sent, the patient agreed to be interviewed, the interview was carried out in their home at a time convenient to them. Consent was obtained prior to beginning the interview. (Appendix III)

5. After the interview was completed, a chart review was done to abstract relevant data such as stage of disease, exact site of the tumor, and whether the patient was attending the TBCC for treatment. If it was not clear from the chart what stage the patient was the Director of Medicine at the TBCC was consulted for a decision.

6. Data was coded and entered into the Multics computing environment at the University of Calgary using the Statistical Package

for the Social Sciences (SPSS) (Nie, Hull, Jenkins, Steinbrenner and Bent, 1975). After the data was edited and preliminary analyses were complete, a BMDP file was created with a subset of variables upon which to perform logistic regression (Dixon, 1985).

Variables : Definition and Measurement

The series of events that lead to a diagnosis of cancer is complex. The use of an illness behaviour model was chosen as a suitable organizing concept as the model included most of the variables which had been identified from the literature. The illness behaviour model that was used has six elements, and the manner in which they were measured in this study is given below.

There were two data collection instruments used in the study, a questionnaire administered by the author in the patient's home, and a chart abstract used to record relevant data from the patient's chart.

The Questionnaire

The questionnaire included several variables from each of the six areas in Cummings' model, and they are listed briefly below:

Demographic

This included age, sex, marital status, education, religion, and income.

Health Threat

This information was collected in a narrative fashion from the patient. The patient was encouraged to describe his/her symptoms, reaction to them, i.e. doctor visits, etc., in his/her own words after a fairly long introduction and explanation of the purpose for asking this information. This explanation was:

" The second topic in the questionnaire deals with the things which you experienced as far as your illness goes. Rather than ask a lot of very specific questions and perhaps miss something that was important in your case, I'm wondering if you could think back to the beginning of this illness and tell me, in your own words, what happened; what you first experienced or felt (any symptoms you may have had); whether they interfered with your everyday activities; and what you did about them. I'd like you to describe, if you can, what symptoms you had, who you went to see, if you did; what happened at each of your visits and some approximate dates, if you can remember."

After the recounting of the patients' experience was complete, the content was reviewed to make sure the type of symptoms, their duration, frequency and severity were recorded.

Patients were also asked how many people they knew who had a diagnosis of cancer or who had died from cancer. Perceived cause of the earliest symptom was also asked.

Knowledge

Level of formal schooling was recorded as a general indicator of

knowledge. Patients were asked if they had heard of several tests sometimes used for the early detection of cancer ; x-ray of the lung, skin examinations, digital rectal examinations, proctoscopy or sigmoidoscopy, physical examination of the breast, cervical smear (pap test), and hemoccult (guaiac). These seven items were taken from a Gallup poll done for the Canadian Cancer Society (Gallup, 1982). In addition, a question specifically relevant to colon cancer was asked. Patients were asked if they knew what a colostomy was, both on the day of interview and six months ago.

Attitudes To Health Care

This includes both a single question of how satisfied the patient had been with the medical care received prior to this recent illness, and a scale developed by Zyzanski to measure satisfaction with medical care (Zyzanski et al, 1974). Zyzanski's scale included three sections; professional competence, personal qualities, and cost/convenience. Only the first two sections were used as the cost/convenience scale is very American in its orientation. The developers of the scale calculated reliability coefficients for each of the three subscales as well as the overall scale. The reliability coefficients for the scale product method of scoring were .75 (Professional competence) , .86 (Personal qualities) , and .68 (Cost/convenience). Each of the two subscales consisted of 12 items which were scored on a 5 point Likert scale ranging from strongly

agree to strongly disagree. Examples of the questions follow. The complete instrument is available in the source publication (Zyzanski et al, 1974).

Examples of statements in the professional competence scale are:

People do not know how many mistakes doctors really make.

Today's doctors are better trained than ever before.

Doctors rely on drugs and pills too much.

No two doctors will agree on what is wrong with a person.

Examples of statements in the personal qualities scale are:

You cannot expect any one doctor to be perfect.

A doctor's job is to make people feel better.

Most doctors take a real interest in their patients.

Most doctors let you talk out your problems.

Health Care System Factors

This section includes some general health care system factors as well as some that were related specifically to this illness episode. General variables included such things as presence or absence of a family doctor, number of years patient had been going to the family doctor, and patients' perception of how well the doctor knew him/her. Variables specific to this illness included number of contacts with the health care system and what the nature of those contacts was (with general practioner, specialist ,etc.).

Social Network Variables

There were two major sections to this area; the Norbeck Social Support Questionnaire (NSSQ) which is designed as a general measure of social support and then several questions designed to collect specific information with regards to this particular illness episode (Norbeck et al, 1983).

A. Norbeck's Questionnaire NSSQ

In this scale, the person is first asked to list all those persons who they feel provide them with personal support or who are important to them. The lead in to this question is:

"Now, I'd like you to think about the significant people in your life. Think about all the persons who provided personal support for you, or who were important to you for any reason. Please think back to (number of months since diagnosis) months ago. Please list these people on the sheet I've given you. I don't need to know who they are, just use a first name or initials, something so that you will know who you had in mind. These people might be a spouse, family, friends, work or school associates, neighbors, health care personnel, minister, priest, or anyone else. Once you have identified the person by initials or first name, please list in the next column what relationship this person is to you."

Once the respondent has listed their significant others, the person then answers several questions with regard to each person that they have mentioned on their list. They rate the answers on a scale from 1-5 with the responses varying from not at all (1) to a great deal (5). The questions on Norbeck's scale are:

How much does this person make you feel liked or loved? (Affect)

How much does this person make you feel respected or admired?
(Affect)

How much can you confide in this person? (Affirm)

How much does this person agree with or support your actions or
thoughts? (Affirm)

If you needed to borrow \$10, a ride to the doctor or some other
immediate help, how much could this person usually help? (Aid)

If you were confined to bed for several weeks, how much could
this person help you? (Aid)

How long have you known this person?

(Answers range from (1) less than six months to (5) more than 5
years.)

How frequently do you usually have contact with this person?
(Answers range from (1) once a year to (5) daily.)

B. Questions Related Specifically to this Illness Episode.

The following information was obtained concerning the
symptom the patient described having prior to going to the doctor, and
was collected using the format already established for Norbeck's
instrument:

Number of people who were contacted about a particular symptom.

Proportion of network members advising the respondent to see a doctor about specific symptoms.

How much influence network members had on the patients' reactions to their symptoms.

How many times respondent talked to network members about the problem.

Proximity of network members residence.

The Chart Abstract

A chart abstract form which was used to record data from the patient file at the TBCC after the interview was the second instrument used in data collection. Data collected from patients' file included sex, marital status, date of birth, place of residence, date of surgery, Dukes stage, site of tumor in bowel, symptoms recorded on chart, whether patient was actually attending the TBCC, and with whom the patient lived. Stage of disease was defined by a method described by Dukes (1932):

A - tumor confined to the intestinal wall.

B - tumor extends into extra intestinal tissue but no lymph nodes are involved.

C - lymph nodes are involved.

D - presenting with widespread metastases to other organs.

Dukes did not actually describe a "D" stage, as his series was limited

to patients with operable tumors, but this has been a modification which is now often used.

Both the questionnaire and the chart abstract form are available from the author on request.

Procedures Used to Increase Reliability of Data

Steps were taken in two different stages to increase the reliability of the data. These two stages were :

1. during the interview for purposes of data collection.
2. after data collection.

Steps Taken During the Interview:

As data were collected from patients retrospectively the following steps were taken during the execution of the study to improve the reliability of data collected. These steps were:

1. Each section of the questionnaire was introduced separately prior to starting that section, with a more complete introduction for the longer and more complicated portions of the questionnaire (social support, history of illness prior to diagnosis). This approach has been shown to produce higher reports of behaviour. The reason suggested for this is that it gives the respondent more time to focus on the topic (Bradburn, 1983).
2. An attempt was made to help the patient structure information. Hindley (1979) suggested that this was especially helpful in getting

individuals to identify exact dates on which events happened. A calendar was provided to which the patient could refer, and if the patient was having difficulty recalling dates, he or she was encouraged to think about illness related events in relationship to other things which had been happening in his or her life around that time.

3. Interviews were done as quickly after diagnosis as realistically possible. Memory loss and distortion are reduced if the time lapse between an event and interview is minimized (Baddeley, 1979).

4. Interviews were done in an environment that was comfortable for patients (usually their homes) and which was potentially less stressful for them than the clinic. Putting patients at ease, and conducting the interview in an unhurried manner facilitates recall (Hindley, 1979).

Steps Taken After Interview Was Done

After the data collection was completed several comparisons were done to assess the reliability of the information collected during the patient interview as well as accuracy of coding and data entry.

1. Sex, marital status, date of birth and date of surgery coded from the chart were compared to these same variables recorded during the interview.

2. The date of first visit to the doctor recorded in the interview was compared to the date of the first visit as ascertained by writing to the family physician.
3. Symptoms recorded during the interview were compared to symptoms recorded in the medical file.

Analysis of Data

The purpose of the analysis was to determine if any of the factors included in Cummings' model was helpful in predicting a late diagnosis. All these are personal, behavioural or health care system factors that could act as risk markers for advanced disease. Initially, variables in each of the six areas (demographic, social support, access to health care, evaluation of health care, knowledge, and health threat) were looked at individually. Variables in each group were assessed univariately for their association with stage of disease at diagnosis. Chi - square tests were used to assess significance of the association between categorical variables and stage of disease and two tailed t-tests were used for continuous variables.

Logistic regression was then used in two stages.

1. Within each of the six areas from Cummings model, component variables were entered into logistic regression. For example, age, sex, and income are component variables in the "demographic" area. Entry limits for the model were .10 (p- value had to be less than .10 for

variables to remain in the regression) and remove limits were .15. (If p-value was greater than .15, the variable was removed.)

2. One or two variables from each area were entered into a multivariate regression which included the whole of Cummings Illness Behavior Model. If there was a summary variable from the area (i.e. knowledge, social network) the summary variable was used in the multivariate regression, otherwise, the variables which were statistically significant in the single area regression were the ones used.

Logistic regression was used for the analysis because the dependent variable is dichotomous, and many of the independent variables are categorical. In a review of the available statistical techniques appropriate to the analysis of relationships involving dichotomous dependent variables, Cleary and Angel (1984) concluded that logistic analysis is most theoretically correct given these circumstances. The logistic model specifies that the odds of a particular outcome (a late diagnosis, in this study) depends on a set of variables x_1, x_2, \dots, x_j in the following manner:

$$\frac{p}{1-p} = \text{Exp} (B_0 + B_1 + \dots B_j)$$

In this equation: p = Probability of late diagnosis

$$\frac{p}{1-p} = \text{Odds of a late diagnosis}$$

B_0 = constant derived from the model.

B_1 = Coefficient of the first variable in the model.

B_j = Coefficient of the j th variable in the model.

Another equivalent equation is for the log odds:

$$\ln p/1-p = B_0 + B_1 + \dots + B_j.$$

The parameters of the logistic model (B_0, B_1, \dots, B_j) which has j variables were estimated by the maximum likelihood approach as described by Schlesselman (1982, p. 246). This requires iterative calculations and were done in BMDP. The relative importance of variables in predicting the probability of a late diagnosis was assessed in terms of a standardized measure (Coefficient divided by the standard error of the coefficient). This statistic can be interpreted as a "Z" statistic. In addition, for the whole model analysis, the results were presented in the form of odds ratios. These were calculated by exponentiating the coefficients using the method described by Schlesselman (1984). The odds ratio is derived from the following formula.

$$\text{Odds ratio} = \text{Exp} (B_1 (x_1^* - x_1') + (B_2 (x_2^* - x_2') + \dots + (B_j (x_j^* - x_j'))$$

or

$$\text{Odds ratio} = \text{Exp} (\sum B_j (x_j^* - x_j')) , \text{ where}$$

x_j^* = value of the j th variable, and

x_j' = value of the reference or baseline category for the j th variable.

In all analyses, the dependent variable was stage of disease (early versus late) . Early stage includes those patients diagnosed as Dukes A or B, and late stage includes those patients with a diagnosis of Dukes C or D.

Limitations of the Study

As a comprehensive model of illness behaviour was used, and included six groups of variables, it may happen that any variable will be reviewed in too superficial a manner to detect subtle effects. . The participation rate was fairly low, (see Chapter 4) so that the results are generalizable only insofar as the participants were typical of the non-participants. Due to the retrospective nature of data collection, several factors, such as loss of memory, and the effects of the recent diagnosis on perception of items asked, are difficult to assess. Given the relatively small sample size (40 in each group), the power of the statistical tests to detect differences when the prevalence of the variable of interest is quite low, is low also.

Summary

This is an analytical study examining the association of stage of disease with various components of factors inherent in an illness behaviour model. Eighty patients were interviewed in their homes and information was collected on patient's knowledge, attitudes about physicians and medical care, social network, access to health care and the nature of the threat posed for the patient by the symptoms. Multivariate analysis was done using logistic regression.

CHAPTER FOUR: RESULTS

An overview of the participation rate of eligible cases is given first followed by a comparison of participants and non-participants. Results of reliability checks on data are also presented before getting into the analysis of data collected specifically for this study. Results of both univariate and multivariate analyses in each of the six areas of Cummings model are presented. Within each content area, the univariate analysis is presented first, followed by the logistic regression analysis which included all important variables in that content area. In the last section, multiple logistic regression results are presented using the most important variables from each of the six content areas of Cummings' model.

Sample Characteristics

Eighty colorectal cancer patients identified from the records of the TBCC and residing in Southern Alberta were interviewed for the study. The participants included 47 males and 33 females ranging in age from 30 to 94 for the males and from 37 to 87 for the females. The male:female ratio of 1.42 compares with a ratio of 1.33 for the new cases diagnosed from 1979 to 1981 in Alberta (Alberta Cancer Board, 1986). The site distribution of their tumors is given in Table 2. Thirty three percent of the tumors were rectal tumors and 67% were located

in the colon. The Alberta Statistics show that 26% of the colorectal tumors in the province are rectal tumors.

Table 2. Distribution of Cases by Sex and Anatomic Location of the Tumour

Site of Tumour	Male	Female	Total	Percent*
Rectum	15	11	26	33
Rectosigmoid	5	0	5	6
Sigmoid	10	10	20	25
Descending Colon	1	2	3	4
Splenic Flexure	2	1	3	4
Transverse Colon	1	1	2	3
Hepatic Flexure	1	2	3	4
Ascending Colon	2	0	2	3
Cecum	10	6	16	20

* Total does not equal 100 due to rounding error.

Participation Rate of Eligible Cases

Documents of all new cases of colorectal cancer identified from the Cancer Registry at the TBCC and from lists of cases with a malignant pathology report, but not yet registered, were reviewed. This included 191 patients. These cases can be allocated to one of four groups:

1. interviewed for the study.
2. refused to participate.
3. eligible, but not interviewed.

4. not registered for more than 3 months after diagnosis.

This last group consisted of cases for whom there was a pathology report in the clinic, but for whom there had been no official registration done by the attending physician. If they were not officially registered, there was no address available at which to reach the patient. The disposition of the cases into the 4 groups above is given in Table 3. The refusal rate for patients contacted was 41%, (56/136)

Table 3. Summary of Disposition of Cases Considered for Inclusion

Refusals		56
- by doctor	(9)	
- by patient	(28)	
- by family	(17)	
- by friends	(2)	
Eligible, not interviewed		55
- too ill or died	(12)	
- moved/unable to contact	(5)	
- too young	(1)	
- language	(4)	
- not registered >3 months	(33)	
Cases interviewed		80
Total cases reviewed		<hr/> 191

The reasons given for refusing were slightly different depending on

who refused. Seventy nine percent of patients who refused did not give a reason, but just said they preferred not to. If family members refused, they most often gave illness for the reason that the patient could not participate. The most common reason given by physicians had to do with the fact that patients were not aware of the extent of their disease, or were having trouble dealing with the diagnosis.

Comparison of Participants and Non-Participants

As the response rate was fairly low in this study, the participants were compared to the non-participants so that the generalizability of these results could be considered. There were 191 cases reviewed for possible inclusion in this study. At the time of study completion 20 patients had still not been registered, and hence, no medical charts existed on those 20. The charts of the remaining 171 cases were reviewed and information on relevant variables was abstracted. Table 4 gives the comparative values for participants and non-participants with regards to sex, marital status, stage, site of primary cancer, age, distance from Cancer Centre, and whether the patient had ever been to the Cancer Centre.

Table 4: Percent of Study Participants and Non-Participants with Various Characteristics As Recorded in Patient Chart

Variable	Participant (N=80)	Non-Participant (N=91)	Chi-Square	P-Value
Sex				
Male	63	54	.98	.32
Female	37	46		
Marital Status				
Married	74	76	.00	1.00
Other	26	24		
Place of Residence				
Calgary	71	83		
Med Hat/Lethbridge	8	1	5.75	.06
Rural	21	16		
Site of Primary				
Rectum	33	37		
Sigmoid	33	27	3.80	.28
Desc/Transverse	14	7		
Ascending/Cecum	21	29		
Stage				
Early	52	46	.45	.50
Late	48	54		
Average Age	64.8	66.9	1.11*	.27
Average Miles from Cancer Centre	22.8	13.4	-1.58*	.12

* Average scores compared using t-tests.

The two groups were very similar except for two areas. Participants were more likely to have been in to the TBCC for consultation and/or treatment. Eighty-eight percent of participants had been to the centre compared with 66% of non-participants (Chisquare = 9.94, $p = .0016$). It also seemed as though there was a tendency for participants to come from outside the city. Potential for bias existed in both these variables. If patients from far outside the city were coming to the TBCC for an extended period of radiation therapy and were going to be in the city, they were approached about being in the study. To assess whether this was a bias or a real difference, participants and non-participants were compared after excluding all those patients whose place of residence was further than 110 miles away from Calgary. All patients within this radius were approached whether they came to the TBCC or not. Examining only the cases who lived within 110 miles of the Cancer Centre revealed that there was still significantly more of the participants who had been to the Cancer Centre. Eighty seven percent of the participants had been to the Cancer Centre at least once compared to 65 % of the non-participants (Chi-square = 8.8, $p=.003$). Of those cases living within 110 miles , the study participants on average lived 13.44 miles and the non-participants lived 10.45 miles away from the City ($p=.497$).

Results of Reliability Checks on Data

There were six comparisons done to assess the reliability of the data.

1. There was 100% agreement between sex as it was coded in the chart and coded in the interview.
2. There were 6 charts with no information on marital status; where this information was present, there was 100% agreement between chart data and interview data. Interview data were used in the analysis.
3. The year of birth was different in one case by one year. The interview date was used.
4. Date of surgery from file was compared with date of surgery from interview. Eighty four percent of patients stated a day that was within 7 days of the actual date. Seventy eight percent stated days within 3 days.
5. Letters were sent to 46 physicians asking them to give the date of the patient's first visit to their office for symptoms which eventually led to a diagnosis of colorectal cancer. Seventy two percent of physicians returned the letter (33/46). Twenty eight of these had usable information. There was an average 21.12 days difference with 69% of the doctors giving dates within a week of the patients' date. Of interest was that in 5 cases (not included in above calculation) it seemed clear that the doctor was not referring to the same event as the patient. The days difference in these cases were 25,60,180,450

and 540. Patient's estimates of days were used in all analyses:

6. Symptoms recorded during the interview were compared with those recorded in the medical chart at TBCC. Symptoms were coded as to whether they were specifically bowel related (bleeding, stool changes, schedule changes) abdominal symptoms not specifically bowel related and generalized signs and symptoms. Table 5 gives results of this comparison.

Table 5: Number of Symptoms Reported by Patient compared to Number Recorded on Chart

	Reported by Patient	Reported by Doctor
Bowel symptoms	73	79
Abdominal symptoms	41	21
Specific symptoms, non abd.	7	5
General signs and symptoms	14	9

Although the overall table did not reach statistical significance, (Chi-square = 6.38, $p=.10$) there were approximately twice as many reports by patients of abdominal symptoms as were recorded in the chart. These included things such as pain, cramps and indigestion.

Single Area Analysis

Demographic Variables

Variables included in this analysis were sex, marital status,

education, religion, employment status, income and age. There were 47 males interviewed and 33 females. Fifty five percent of the males were diagnosed in late stage versus only 39% of the females. This difference was not statistically significant. The average age of early stage patients was 66.57 compared with 62.36 for late stage ($t = 1.45$, $p = .15$) Table 16 summarizes the categorical demographic variables. In a univariate analysis, none of them was associated with the dichotomous dependent variable - stage of disease at diagnosis. For 2 x 2 tables corrected Chi - Squares were used to assess association.

Table 6: Demographic Factors

Factor	Level	Late	Early	Chi-square	p-value
Sex	Male	26	21	.83	.37
	Female	14	19		
Marital status	Not Married	12	11	0.00	1.0
	Married	28	29		
Education	<High School	25	21	.46	.50
	High School	15	19		
Religion	R.C.	9	8	5.45	.36
	United	10	7		
	Protestant	10	7		
	Other Christian	7	14		
	Other	4	4		
Employment	Not working	18	21	.20	.65
	Working	22	19		

Income	< \$23,000	18	20		
	> \$23,000	19	16	.126	.72

Logistic Regression - Demographic Variables

Regressors entered into the model included age, sex, marital status, religion, employment status and income. Stage of disease was the dichotomous dependent variable. There were 73 cases in which all of the demographic variables were present, but no term passed the remove and enter limits. These results are consistent with those found in the univariate analysis.

Health Threat

The second area of interest was that of the nature of the health threat. The health threat variable includes those elements which describe the symptom experience as perceived by the patient as well as the interpretation of those symptoms and responses to them. There are both general and specific variables included in this analysis.

Variables included are past experience with cancer, number and type of symptoms, duration of symptoms, effect of symptoms on patients everyday life, and patients' response to the symptoms. Perceived cause of presenting symptoms was also examined.

Past Experiences With Cancer

Patients were asked how many of their friends and relatives had had cancer and also how many of the friends and relatives they had

died from cancer. There was virtually no difference between early and late stage patients on either of these variables. Early stage patients knew an average of 2.67 people (friends plus relatives) versus 2.63 for late stage ($p=.89$). Similarly, both groups knew similar numbers of people who had died from cancer. Early cases knew on average, 1.88 people who had died versus 1.78 for late stage cases ($p=.76$).

Symptoms

Symptoms, their characteristics, and the response they prompted in the patients were the major constituent of the health threat variable.

Nature of Symptoms

This included the number, type of symptoms reported, their frequency and the severity. Severity of the symptom was assessed by the extent to which they interfered with the patients work, family life and social life. An index was developed to provide a quantitative measure of the symptom impact.

Although symptoms were given in response to an open ended question, they were coded as being one of the following: bleeding, abdominal pain, abdominal symptoms other than pain (indigestion, gas, etc.), stool changes, schedule changes (i.e. increasing frequency of bowel movements, constipation), functional (interference with the ability to carry out daily activities), general (i.e. tired), specific non-abdominal (i.e. pains in legs, neurologic symptoms). Table 7 provides

the distribution of the earliest symptoms noted by the patient.

Table 7: Number of Patients Noticing Particular Initial Symptoms

<u>Symptom</u>	<u>Early</u>	<u>Late</u>	<u>Total</u>
Bleeding	12	12	24
Abdominal pain	6	11	17
Abdominal complaints, not pain	2	2	4
Schedule changes	11	4	15
Stool characteristics	1	2	3
Functional complaints	3	2	5
Other general signs and symptoms	2	1	3
Other specific signs and symptoms	<u>1</u>	<u>0</u>	<u>1</u>
	38	34	72

Bleeding was the most common symptom noticed first with abdominal pain and changes in scheduling of bowel movements next most frequently mentioned. By grouping the symptoms further, some interesting observations can be made. Symptoms were grouped into three groups defined by their broader category, whether they were specifically bowel related (bleeding, schedule changes, stool characteristics), abdominal symptoms, but not specifically bowel related, and general (non-abdominal, non-bowel) symptoms. Table 8 gives the percent of early and late cases who had at least one of these symptoms.

Table 8. Percent of Early and Late Cases With at Least One Symptom in Group

<u>Symptom</u>	<u>Early</u>	<u>Late</u>
Bowel	79	72
Abdominal	39	66
General	21	25

Frequency of Symptoms

The total number of symptoms reported prior to going to the doctor was examined. There was no difference in the number of symptoms experienced by the two groups (Table 9).

Table 9. Number of Patients Experiencing a Certain Number of Symptoms Prior to First Doctor Visit

	<u>Number of Symptoms</u>				
	0	1	2	3	4
EARLY	2	25	9	2	2
LATE	8	17	9	4	2

Frequency of Episodes

A frequency score was calculated which included all symptoms reported by the patient prior to going to the doctor. This was done by adding the number of occurrences or "episodes" per month for all the symptoms reported. Late patients had on average 32.1 symptom

episodes per month versus 30.7 for early ($t = -.18$, $p = .85$).

Severity of symptoms

For each symptom reported, patients were asked to rate on a 5 point scale, how much this particular symptom interfered with their work life, family life, and social life. The rankings for each of these areas were summed to give a severity score. There was no difference on a symptom by symptom basis, and the severity score was not different between the two groups either ($t = .29$, $p = .77$).

Reaction to Symptoms

Two variables were considered here: perceived cause of symptoms and the length of time elapsed before patients went to the physician. The patients were asked, when they went to the doctor initially, what they thought may have been causing their symptoms. About half of the patients did not volunteer an opinion about what they thought had been causing the symptoms. Table 10 gives a summary of the reasons that were given.

Table 10. Number of Early and Late Cases Attributing Symptoms to Specific Causes

<u>CAUSE</u>	<u>EARLY</u>	<u>LATE</u>
No cause given	20	23
Hemorrhoids	2	4
Chiropractor	0	1
Ulcers	3	1

Table 10. Number of Early and Late Cases Attributing Symptoms to Specific Causes (cont.)

<u>CAUSE</u>	<u>EARLY</u>	<u>LATE</u>
Diet or food allergies	1	1
Gallbladder	1	0
Getting old	0	1
Irritated colon	0	1
Polyp	1	0
Fissures	1	1
Cancer	8	2
Constipation	2	0
Hernia	0	1
War injury	0	1
Bugs from Far East	1	1
Heart medication	0	1
Diverticulitis	<u>0</u>	<u>1</u>
	40	40

Early and late stage cases were classified as to whether they attributed their symptoms to cancer or to some other cause. Eight of twenty early cases (40%) said, in an open ended question, that they had thought their symptoms may have been due to cancer. This is compared to only 13% of late stage patients. Conversely, late stage patients tended to give more non-cancer reasons for their symptoms (Chisquare = 2.72, $p = .10$). These reasons were often other illnesses.

Going to the doctor in response to symptoms was another variable in the perceived health threat area. The 32 late stage patients who reported having at least one symptom prior to going to the doctor had an average time lapse of 466 days before going to the doctor. This is

compared to 409 days for early patients. This difference is not significantly different. ($t = -.19$, $p = .85$)

Logistic Regression - Health Threat

Variables chosen as regressors for the logistic model were chosen on the basis of their conceptual relationship to the dependent variable rather than on any strict statistical basis. Component variables were used rather than summary variables. In this health threat regression, regressors included perceived cause of symptoms (cancer versus others), days lapsed between noticing first symptom and first visit to the doctor, specific type of symptom (bleeding, abdominal pain, abdominal symptoms other than pain, change in schedule of bowel movements, stool changes, symptoms which interfere with daily activities, generalized symptoms, and specific, nonabdominal symptoms) severity of symptoms and frequency of symptoms. Table 11 gives the results of this regression. Attributing the cause of symptoms to causes other than cancer was significant in predicting late disease.

Table 11: Results of Multivariate Logistic Regression of Health Threat Variables (n=65)

	Coefficient	S.E.	Coefficient/ S.E.
Attribute symptoms to cause other than cancer	.711	.418	1.70
Constant	-.675	.418	-1.62

Knowledge

Knowledge was the third area investigated. Several questions were included in the questionnaire to measure knowledge. Level of education measures knowledge in a general sense, whereas specific questions about other cancer prevention techniques plus two questions about colostomy measured knowledge specific to the topic in question.

Although it was not statistically significant, more of the early cases (50%) had at least a high school education than late cases (38%). Patients were asked if they had ever heard of several tests sometimes used for the early detection of cancer. Table 12 gives the percent of patients who knew about each of these tests.

Table 12. Percent of Early and Late Patients with Knowledge of Early Detection Techniques for Cancer

TEST	EARLY	LATE	CHI-SQUARE	P LEVEL
X-ray of lung	69	63	0.15	0.69
Examination of skin	56	53	0.15	0.90
Rectal examination	62	65	0.01	0.93
Proctoscopy/sigmoid.	51	53	0.00	1.00
Breast physical exam.	77	88	0.88	0.35
Pap test	72	93	4.47	0.03
Hemoccult test (Guiac)	28	18	.75	.39

In addition to these early detection techniques, patients were asked if they knew, on the day of the interview, what a colostomy was. If they said they knew what it was, they were also asked if they knew

what it was six months ago. There was no difference between the percent of early and late cases who knew what a colostomy was either at date of interview or six months previously.

It is interesting that the only early detection technique that the early groups had heard of substantially more often than the late groups was the one specifically associated with the colorectal cancer. The responses for the knowledge items (excluding educational level) were summed to give a knowledge score. Of the nine items which asked if the patient had ever heard of these procedures, late patients had, on average heard of 5.5 of them compared to 5.4 for early cases ($t = -.17$, $p = .867$)

Logistic Regression - Knowledge

The variables entered as regressors included all of the variables listed in Table 8 above plus educational level and the level of knowledge about colostomy. Early patients had heard of hemoccult tests more often than had late, but late patients had heard of Pap tests significantly more often than early patients. (Table 13)

Table 13. Results of Logistic Regression Analysis with Knowledge Variables (n=76)

	Coefficient	S.E.	Coefficient/S.E.
Knowledge of Hemoccult	.553	.297	1.86
Knowledge of Pap	-.899	.360	-2.50
Constant	-.953	.413	-2.31

Health Care System

The fourth area considered was that of the health care system. The variables included in this rather broad ranging category are either of a general nature or specific to this illness episode. The general variables are: presence of a family doctor, number of years attended that doctor, and the patient's perception of how well doctor knows him or her.

The variables which are specific to this illness and which are included in this analysis are: the number of doctor visits, the type of doctors involved, and the time period between relevant events in the process of diagnosis.

General Variables

These variables are concerned with the patients' usual health care practices prior to this illness. Presence of a family doctor, number of years the patient has been attending that doctor, patient perception of how well the family doctor knows him/her, and the geographical location of the patient's residence in relation to location of family doctor are the variables included here. There was no difference between the number of patients in the two groups who had a regular family doctor. Thirty two early stage and 34 late stage patients said they had a family doctor (Chi-square = .08, $p = .15$). Early stage patients had been going to their doctors for an average 13.6 years, compared to 8.8 years for late stage patients ($t = 1.43$, $p = .16$). Sixty eight percent

of both early and late patients felt their doctors knew them fairly well. There was also no difference between patients who lived on a farm and those who lived in the same town/city as their physician.

Variables Specific to This Illness Episode

The intent of this analysis was to determine if there was a difference between the experience of early stage and late stage patients once contact with the health care system had been established. This was measured in two ways:

1. by describing the number of doctor visits and by describing the type of doctor.
2. by examining time lags between relevant events in the course of diagnosis. Table 14 gives a summary of the doctor contacts.

Table 14. Average Number of Doctors Seen and Doctor Visits Experienced by Early and Late Cases

Variable	Early	Late	t	p-value
Number of Doctors seen	2.30	2.60	-1.36	0.179
Number of GP's seen	0.95	1.13	-1.71	0.091
Number of visits to GP	2.30	3.40	-2.14	0.036
Number of specialists seen	1.47	1.47	0.00	1.000
Number of visits to specialists	2.67	3.00	-0.95	0.347
Number of visits to emergency	0.10	0.08	1.04	.0305

Late stage patients had significantly more doctor visits than early

stage patients. Although the number of specialists seen was the same for early and late cases, late cases saw more general practitioners, on average.

Several events were recorded as being important in the documentation of the patient's contacts with the health care system. These events included date of first doctor visit, date of referral to specialist, and date of diagnosis (Time from first symptom to first doctor visit was included under the analysis of health threat). Figure 2 portrays the average days time lag between important events in the diagnostic process. The analysis for Figure 2 was restricted to patients for whom all these events were recorded (33 early stage patients and 24 late).

Figure 2. Time Lapse Between Relevant Events in the Diagnosis Process.

Early	I	_____409_____(S.E.180)_____	*	_____89_____	*	_____75_____	II
Late	I	_____467_____(S.E. 245)_____	*	_____115_____	*	_____49_____	II
I = First Symptom * = First visit to doctor * = Referral to specialist II = Diagnosis							

Logistic Regression - Access

This analysis includes those variables which reflect proximity to and use of the health care services. Regressors in the model were the number of visits to the family doctor, presence of a family doctor, years attended the family doctor, and the number of days from the first

visit to diagnosis. The only variable which predicted stage of disease was the number of visits to the family doctor prior to diagnosis. An increasing number of doctor visits increased the probability of a late diagnosis (Coefficient .193, S.E. .116, Constant -.641) (n=74).

Attitudes to Health Care

The fifth factor assessed, attitude toward the health care system, consisted of a summary of the patient's own assessment of their past contact with the system. Patients were asked a general question about their overall satisfaction with medical care they had received in the past (prior to this recent illness). Both the early and late patients had been satisfied with their past medical care. Ninety percent of early cases and 87% of late cases said they were either satisfied or very satisfied with the medical care they had received in the past.

In addition, attitudes to health care were measured by a scale developed by Zyzanski et al (1974). There were two subscales from Zyzanski's original work included here. The Professional Competence score included 12 items, as did the Personal Qualities score. Excluding on an item by item basis those people who had no opinion about the item, no single item was significantly different between early and late stage cases. Similarly, there was no difference on the Scale Scores. (Table 15)

Table 15. Professional Competence and Personal Qualities Scores

	<u>Mean Score</u>		<u>S.D.</u>		<u>t</u>	<u>p-value</u>
	<u>Early</u>	<u>Late</u>	<u>Early</u>	<u>Late</u>		
PQ Score*	1.72	1.73	.59	.70	-.08	.93
PC Score*	.73	.85	.57	.38	-1.07	.289

* PQ = Personal Qualities Score

* PC = Professional Competence Score

Logistic Regression - Attitude

The logistic regression model included all 80 case and included the two scale scores mentioned above, Personal Qualities and Professional Competence, as well as satisfaction with medical care received in the past. None of these three terms passed the remove and enter limits.

Social Support

Social support was the last area considered. This analysis was done to determine if there were any aspects of the patient's interpersonal relationships with other people that were associated with a late diagnosis of colorectal cancer. The variables included here were primarily those from Norbecks' Social Support Instrument (Norbeck et al, 1983) with a few others added as a result of observations in the literature.

Norbeck's Instrument

This instrument is designed to measure the amount and type of support available to an individual (Norbeck et al, 1983). Scores for the three types of support - affective, affirmational and aid plus three properties of the social network (duration of relationships, frequency of contacts and the number in network) are summarized in Table 16.

Table 16. Means, Standard Deviations on NNSQ for Early and Late Stage Patients

NNSQ Subscales	Early (n=40)		Late (n=40)		P-value
	Mean	S.D.	Mean	S.D.	
Affect	73.95	34.08	74.20	42.07	.98
Affirmation	64.90	35.34	67.03	38.03	.80
<u>Aid</u>	<u>49.63</u>	<u>32.36</u>	<u>43.60</u>	<u>32.34</u>	<u>.41</u>
Total Support	188.48	95.46	184.83	104.52	.87
Number in Network	10.25	4.90	11.13	6.33	.49
Duration of Rel'ships	50.80	24.62	53.95	30.11	.61
<u>Frequency of Contact</u>	<u>22.60</u>	<u>13.99</u>	<u>28.78</u>	<u>19.68</u>	<u>.11</u>
Total Network	83.65	42.53	93.85	55.21	.36

Average duration was calculated by dividing the total duration of relationships by the number in the network. The average duration score of relationships were 4.94 for early and 4.88 for late stage ($p=.25$).

This variable was coded as (1) less than six months, (2) 6 to 12 months, (3) 1 to 2 years, (4) 2 to 5 years, and (5) more than 5 years. This meant that most of the patients in both groups had known their

network members for more than five years. Sources of support were coded into nine categories and the results for both stages are given in Table 17.

Table 17: Mean Number of Network Members by Category of Member

	Early	Late	t	p-value (two-tailed)
Spouse/Partner	.73	.73	.00	1.000
Family	6.33	5.55	.97	.335
Friends	2.65	4.05	-1.80	.075
Work/School Associates	.28	.20	.44	.658
Neighbors	.15	.35	-1.14	.259
Health Care Providers	.00	.05	-1.43	.156
Minister/Rabbi	.10	.20	-.84	.402

No differences were statistically significant. The only difference approaching statistical significance was the number of friends listed in the network. Early patients listed an average of 2.65 friends and late patients listed 4.05. Early cases had more family and fewer friends.

Other Measures of Social Support

As stated in the section on demographics, 73% of early cases and 70% of late cases were married. There was no difference on marital status or employment status, both variables which theoretically could provide sources of social support.

Because there was a suggestion from the literature that events

recorded specifically with relation to a particular illness event are more predictive of behaviour than generalized measures (Berkanovic, 1982), an attempt was made to examine circumstances specifically related to the symptoms preceding a diagnosis of colorectal cancer. Patients were asked how many people they had spoken to about the symptoms experienced prior to going to the doctor and how much influence these people had on their subsequent actions. Early patients spoke to others on average of 2.6 times compared with 2.2 for late cases ($t=.74$, $p=.46$). Early cases estimated an average influence score of 1.9 "some to a great deal" versus 1.2 "very little to some" for late ($t=1.82$, $p=.07$). This influence question was scored on a 4 point scale (0=none, 1=very little, 2=some, 3=a great deal).

Logistic Regression - Social Support

Variables entered into the regression were the total number of individuals listed in network, number of family in network, presence of spouse or partner, number of friends in network, number of neighbors in network, number of ministers in network, membership in groups, average duration of relationships, distance lived from network members, average functional support from network members, average influence from network once a symptom is present, frequency of contact, affective support, affirmational support, and tangible aid.

Stage of disease was the response variable, and the social support variables listed above were entered as regressors. Number of

friends, tangible aid, number of neighbors and number of religious people (ministers, priest, etc.) in support group were all significant in predicting late stage disease. Late stage patients had more friends, more ministers, more neighbors, and less perceived tangible aid than early patients. Table 18 gives the logistic parameters.

Table 18: Results of Logistic Regression on Social Support Variables (n=80)

	Coefficient	S.E.	Coefficient/S.E.
Number of Friends	.288	.101	2.85
Number of Neighbors	.541	.353	1.53
Number of Minister/Rabbis	1.000	.534	1.87
Tangible Aid	-.029	.011	-2.64
Constant	.102	.428	0.24

Full Model Analysis

The most important variables from each of the six content areas in Cummings model were entered together into a logistic regression model. A slightly different rationale was used for choosing the variables from each of the areas and Table 19 summarizes the reasons. Basically, the variables were chosen either because they were the summary variable for the area, or because they had been important in the single area multiple regression.

Table 19: Summary of Rationale for Choosing Variables for Multiple Logistic Regression

Content Area	Variables in Model	Rationale
Knowledge	Knowledge Score	Summary variable of knowledge items.
Social Support	Total Functional Support	Summary variable of perceived support.
	Total Network Score	Summary of quantity of support.
Access to Health Care	Number of visits to Family Doctor to Diagnosis	Statistically significant in single area regression.
Evaluation of Health Care	Personal Qualities Score	Summary of Subscale
	Professional Competence	Summary of Subscale
Health Threat	Attribution of symptoms	Statistically significant in single area regression.
Demographics	Age Sex	Included as two demographic variables of general interest in health behaviour literature.

When these nine variables were included in a regression model, two of them were significant as predictors of late stage disease. These were the tendency of late stage patients to attribute symptoms to something other than cancer, and to have had more visits to their family doctor prior to diagnosis. Table 20 gives the coefficients from the multiple

logistic regression which included variables from all six areas of the illness behaviour model.

Table 20: Results of Logistic Regression of Variables from all Six Areas (n=80)

Variable	Coefficient	S.E.	Coefficient/S.E
Number of Visits to Family Doctor	.216	.110	1.96
Attribution of Symptoms to Causes Other Than Cancer	.786	.428	1.84
Constant	-1.22	.534	-2.28

Table 21 presents the same data in the form of odds ratios. The odds of a patient being diagnosed in late stage if he/she had not attributed cause of symptoms to cancer and if he/she had seen a general practitioner 9 times, was 12 compared to a patient who had seen a general practitioner only once and who thought his/her symptoms may be due to cancer.

Table 21. Odds Ratio* for a Late Diagnosis by Number of Visits to General Practitioner and Attribution of Cause of Symptoms

Number of visits	Attribution of Cause of Symptoms	
	Cancer	Not Cancer
1	1.00*	2.72
3	1.54	3.38
5	2.37	5.21
7	3.65	8.02
9	5.63	12.35

*Reference category.

* Odds ratio after adjustment by multiple logistic regression for knowledge score, Professional Competence Score, Personal Qualities Score, total functional support, total network score, age, and sex.

Summary

Of the six areas included in the model used to assess the differences between early and late stage colorectal cancer cases, two areas, demographics and attitude toward health care, did not help at all in predicting late stage disease. In the single area multiple logistic regression, at least one variable in each of the remaining four areas was helpful in predicting late stage. More of the late stage patients had heard of Pap tests and less of them had heard of Hemoccult tests. The composition of the support network varied. Late stage patients had more friends, neighbours, and ministers in the networks than early patients. In addition to this difference, late patients felt they had less tangible aid available to them. Late stage patients had

experienced significantly more visits to their family physicians prior to diagnosis. Early and late stage patients differed in their attribution of cause of the symptoms they had experienced. Late patients were less likely to say they thought, at the time they were having the symptoms, that the symptoms could have been caused by cancer.

In the full model logistic regression, two variables remained in the model and were significant contributors to the prediction of late stage diagnoses. The variables were attribution of cause of symptoms and the number of visits to the general practitioner prior to diagnosis. Therefore, in this study, specific aspects of the health care system and the perceived health threat were the two areas most strongly associated with stage of cancer at diagnosis.

CHAPTER FIVE: DISCUSSION

The initial discussion in this chapter concerns the reliability of the information collected and the generalizability of the results. Following this, the results from the single area and full model analysis are discussed. Finally, the discussion is summarized and some implications for future research are suggested.

Participants, Non-Participants and Reliability of Data

There was a higher proportion of males in this sample than in the population of colorectal cancer patients in Alberta in recent years. There was also a slightly lower proportion of rectal cases. This difference is somewhat interesting as males have more rectal tumors than females in this province. Forty three percent of male colorectal tumors are rectal primaries compared with 34% in females (Alberta Cancer Board, 1986). Fifty one percent of those people approached to be in the study agreed to be interviewed. The refusal rate was higher than anticipated. The impression gleaned from interacting with the patients, was that for many of them, there were many things to deal with at this point in their lives. Not only had they had a very recent diagnosis of cancer but many of the patients were given radiotherapy or chemotherapy. Many of them were waiting for decisions about one aspect of their treatment or another, and several patients suffered side effects from the radiotherapy. Many of the people who refused gave the

impression that they just could not, or at least chose not to, deal with one more new thing in their lives. The immediate post diagnosis period is very stressful.

The slight excess of males may have been due to a tendency for males to participate at a higher rate than females, but is probably at least partly a reflection of a slightly higher proportion of males being diagnosed over the time period of this study. Fifty six percent of all the patients identified as being eligible for this study were males, compared to 51% of all colorectal cancer patients diagnosed in Alberta over a three year period (Alberta Cancer Board, 1986).

The fact that patients who had been to the TBCC at least once were more likely to participate did seem to be a real difference. This is somewhat difficult to explain, as the study was identified with the university and not specifically the Cancer Centre. Patients are referred to the Cancer Centre by their physicians. It could have happened, although there was no direct evidence of this, that physicians who referred patients to the Cancer Centre, also encouraged or at least did not discourage, patients from taking part in the study. Several patients mentioned that they had discussed the study with their physicians.

Non-participants were slightly older than participants, but overall there did not seem to be biases in the participating group that would seriously limit the ability to say that these results were generalizable to the patients diagnosed with colorectal cancer over this time period. As the sex distribution of cases diagnosed during this

specific time period appeared somewhat different as far as sex ratio goes, caution should be used in generalizing results to Alberta in general.

Reliability of Information

Patients were able to reliably recall the date of their surgery. The accuracy with which patients could recall a particular other event (i.e. first visit to doctor for reasons which eventually resulted in a diagnosis of cancer) was somewhat less. However, the fact that the "standard" against which patients dates were measured (Doctor's report of date) is also subject to interpretation, makes this comparison somewhat less definitive. Nevertheless, time lapses between somewhat loosely defined events are calculated on the basis of patient estimates of dates and should be used with caution.

There did seem to be a difference between the symptoms reported on the chart and what the patient reported. It appears in this study that physicians may selectively under-report abdominal symptoms. However, this may have been due to the nature of the information in the patient file. The TBCC is a tertiary referral centre and the records in the patient file almost always include patient histories taken by clinic physicians at TBCC or the hospital record, but rarely the original report of initial visits to family physicians. This apparently low reporting of certain symptoms may be due to the fact that these records are often generated quite some time after the initial visit to the doctor, and in most cases, after the diagnosis is made.

Single Area Analysis

Demographic

The most notable characteristic of the analysis in this area is that there were no statistically significant associations either in the univariate or multivariate analyses between stage and any demographic factors. Contrary to Antonovsky and Hartman's (1974) conclusion that older people delayed more than younger, the difference in this study, although not statistically significant, was in the opposite direction. Although demographic variables are often instructive in a general sense in predicting utilization of health services, they were not relevant to determining stage of disease at diagnosis of colorectal cancer in this study.

Health Threat

Past Experience

Past experience with cancer was not different between early and late stage cases. This is not the same as other studies that have suggested that past experience may be important. It may be that it is more the nature of past experience, whether it was a positive experience or a negative one. This study did not collect that type of detail.

Type of Symptoms

Bleeding was the most common symptom reported by these

patients. This is somewhat different than has been reported by others.

Abdominal pain is the most common symptom in most series.

Abdominal pain was the second most common symptom in this study, but it was more common in late stage patients. This may generally be a reflection of earlier diagnosis of colorectal cancer in the time since the other series were studied. Vellacott et al (1987) suggested that more cases were being diagnosed in earlier stages now than 10 years ago. On the other hand, 8 patients (6 late and 2 early) had no symptoms at all, but had their disease diagnosed incidentally. Winawer (1983) suggested that early stage disease may be largely asymptomatic. These results do not support that at all. Late and early patients experienced virtually the same number of symptoms prior to their first doctor visit.

Symptoms were grouped according to their direct physiological relevance to the diagnosis. Bleeding, changes in bowel schedule and stool changes were grouped as bowel symptoms; abdominal pain and other abdominal symptoms were grouped as abdominal complaints and other symptoms were grouped as general. This last group may have been the least directly related to bowel disease, both in the minds of the patients and perhaps in physicians'. In fact, this method of grouping did in some way support the notion that bowel specific symptoms were noted more often in early cases, and generalized symptoms and abdominal symptoms were noted more often in late. The greatest difference was in abdominal symptoms. Sixty six percent of late cases experienced abdominal symptoms compared with 39% of

early cases. If either patient or physician delay was a factor in late diagnoses it perhaps could be a result of non-specific clues, such as abdominal symptoms, that were not specifically bowel related.

Severity of Symptoms

The impact of symptoms was examined, as it was reasoned that, if symptoms were fairly severe, and were present fairly often, that this would cause both patients and physicians to search for an explanation with more speed. McArthur and Smith (1984) found that patients whose symptoms produced considerable initial discomfort went more quickly to the doctor. In the present study both the frequency scores and severity scores were similar in early and late groups. This could have been because the scale was not sensitive enough to detect the variety of ways symptoms were described. For example, in an extreme case, a patient may have one or two very severe pain attacks which caused them to go to the physician. The frequency score would have been low, and the patient may have answered that it didn't interfere with work, or social life because it had been a severe, short attack and he/she had dealt with it right away. It seemed as though the questions "How much did your symptoms interfere with your work (social, family) life?" were interpreted differently by different people. The questions were coded on a 1-5 point scale and were coded as the person answered, but it seemed in many cases that the variable was not capturing what was being interpreted by the interviewer. For example, one person who had 10-20 bowel movements per day said the symptoms did not interfere with his work life at all as he planned his own work and just made sure

he was always near a toilet.

Reaction to Symptoms

An attempt was made to capture the reaction of patients to their symptoms. A similar number of early and late cases (20 early and 23 late) had no opinion about what had been causing their symptoms. However, the ones who did express an opinion did vary in their attribution of cause for the symptoms. Late patients were more apt to attribute their symptoms to something other than cancer and early patients said they thought it may have been cancer. There are two possible explanations for this difference. The first is that perhaps late stage patients had more coexisting disease, which may, in fact have made it more difficult for both patient and physician to make a diagnosis. The second is that, even in the presence of any competing diagnoses, some patients are more willing and able to face the fact that their problem may be cancer and therefore act promptly in response to symptoms. There is no way of knowing from this study whether the early and late patients differed with respect to other coexisting medical problems. There is suggestive evidence from other studies that patients who are more able to call cancer "cancer" have their disease diagnosed earlier. Response time to visit a physician is another reaction to symptoms. Although early patients went to the doctor somewhat sooner than late patients (409 days versus 466) the difference was not significant.

In the multivariate logistic regression including all the health threat variables, attribution of cause was the only regressor which

was significant in predicting stage after controlling for the effects of the other variables.

Knowledge

Although the summary knowledge score was not different between early and late cases, on an individual knowledge item basis there were two differences. The only statistically significant difference was the fact that late cases had more often heard about the Pap test. This was not a sex related difference (81% of men and 82% of women said they knew about the Pap test) This result is also not an extreme example of a trend for late cases to have a higher level of knowledge in general about early detection tests. Of the 7 early detection tests, late cases had a greater knowledge of 4 tests (Pap test, physical examination of the breast, proctoscopy, rectal examination) , but early cases had a greater knowledge of 3 tests (x-ray of lung, examination of the skin, hemoccult)

It is somewhat interesting that the only early detection technique that the early group had heard of substantially more often (although it was not statistically significant) than the late group was the one specifically associated with the type of cancer in question in the present study. This did not appear to be a result of their having been more exposed to hemoccult in the context of this present illness. Patients were asked if they had heard of hemoccult, if they had ever had one, and if they had had one in the past year. There was no difference in the number of patients who had had one in the past year

(23% of both groups reported having had one) but 45% of early cases reported ever having had one, compared to only 33% of late cases. Therefore, there is a suggestion that specific knowledge of hemocult, both having heard of the test and having experienced it, is associated with early diagnosis. DiClemente and Temoshek(1984) also found that a lack of knowledge specific to the type of cancer in question (melanoma) was associated with late stage diagnosis. An alternative explanation of the association with knowledge of hemocult and an early diagnosis is that these patients had had bowel problems in the past (hence, the more frequent exposure to hemocults) and that perhaps they were being followed more closely with regards to potential bowel problems.

In the multivariate logistic regression the knowledge about hemocult and knowledge of Pap tests both contributed to prediction of stage at diagnosis, although the difference was in the opposite direction for the two variables. The association of knowledge about Pap test with a late diagnosis is difficult to explain, and may have been a chance finding.

Health Care System Variables

Visits to General Practitioner

The only "general" health care system variable measured that showed any difference was that of the number of years that patients had been attending their family physicians. Although it did not quite reach statistical significance, there is a suggestion from this study

that a long term relationship with a family doctor may be associated with early diagnosis. This may reflect a good working relationship where changes in health status are able to be acted on effectively because the physician knows the patient's history and reactions very well. On the other hand, it is perhaps possible that people who tend not to have long standing relationships with physicians tend to be different in other areas that predispose one to a late diagnosis. For example, people who don't have long standing relationships with physicians may be "non-health" oriented generally, and may be less perceptive of symptoms when they occur.

There did seem to be some differences in the profile of the contacts between the health care system and early and late cases. The variable which was statistically significant in both univariate and multivariate analysis was the number of visits to the family doctor. This in and of itself, of course, does not cause a late diagnosis, so a look at some of the reasons behind those multiple visits is warranted. A "qualitative" look at these cases suggests some reasons for the increased number of visits in late stage patients. Late cases, in addition to having had more visits to the general practitioner, also had more general practitioners involved in their care. The larger number of visits could have been partly explained by the fact that patients saw more than one G.P., however, this did not seem to be the case. By examining the individual late stage cases who had contributed to the higher average number of visits for late stage patients, as well as the 6 late stage cases who had seen more than one G.P., it was clear that it

was not the same cases. There was only one case where the patient had seen more than one G.P. and had been to a G.P. more than six times. In five of the 8 cases where the patient had been to a G.P. more than 6 times, it seemed clear that the patient had been treated for another disease. These varied from gynecological problems, diverticulitis, prostate problems and neurological problems. In addition, in one case, the large number of visits seemed to have been at least partially a result of the patient postponing surgery.

The six late cases who had seen more than one G.P., had some similarities. None of them attributed their symptoms to cancer and three of them had seen a G.P. in different geographic locations (Men who worked out of the city). Although the only variable that contributed significantly to the prediction of a late diagnosis was the number of visits to the family doctor prior to surgery it is clear that this may be a result of varying causes. It seems in some cases, a coexisting or previous illness may have contributed and it is also possible that the patient has a role to play in the number of visits.

Delay

Looking at time lapses between relevant events, or "delay" as many authors have termed it, was not very helpful in this study. There were no significant differences. There was a slightly longer "patient delay" (time from first symptom to first doctor visit) for late stage patients and slightly longer period of time from first visit to referral to specialist. This makes sense in that late patients had on average, more visits to G.P.s and saw more than one G.P. However, the overall

time from first visit to diagnosis was virtually the same for early and late cases. Once late stage patients got referred , diagnosis followed relatively quickly. Therefore, although this specific health care system variable was significantly associated with late stage throughout the analysis, it is apparent that the increased number of visits to a General Practitioner comes about as a result of a variety of circumstances. It is fair to conclude, however, that the profile of contacts with the health care system differs for late and early stage patients.

Attitudes toward Health Care

The measurement of attitude to health care (primarily physicians) did not provide much useful information in this study. Early and late cases rated the physicians personal qualities exactly the same. Late cases scored the physicians slightly higher on the professional competence scale, although it was not statistically significant.

Social Support

It seems as though social support may be of some assistance in explaining the differences between early and late stage patients. In the univariate analysis, of the six components of Norbeck's scale, late stage patients had higher average scores in all three of the "quantity" measures (number in network, duration of the relationships, and frequency of contact) and in 2 of the 3 "quality" measures (affectional support, affirmational support). The only one where late patients had a lower score was in tangible aid (perception of short term help and long

term help if confined to bed).

Although no social support variables were significantly different in the univariate analysis, in the multivariate logistic regression, several were statistically significant in helping to predict late stage disease. The composition of the network was different for late stage patients. They reported having more friends, more ministers and more neighbors in their network than early stage patients.

Other researchers have examined the effects of differing composition of support networks. Two previous studies have suggested that friend oriented networks (as opposed to kin oriented) will facilitate a better outcome with regards to health care utilization (Salloway and Dillon, 1973; Birkel and Reppucci, 1983). The present study suggests the opposite. However, the studies are not directly comparable. In Birkel and Reppucci's study, "need" for health care services was determined by health professionals, after which subjects were offered services. Respondents were not responding to a need perceived by themselves. In the other study cited (Salloway and Dillon, 1973) they were responding to a perceived need but it was a very loosely defined need ("the last time you thought you might be sick"). In any event, in the present study, having more network members that were non-family was associated with a late stage diagnosis. This is in contrast to the two studies above where friend networks were associated with better health outcomes.

Full Model Analysis

In the analysis which included variables from all six areas, there were two variables which remained in the model. Attribution of cause of symptoms (health threat) and number of visits to a G.P. (health care system) prior to diagnosis were the two most important variables, after accounting for the effects of the other areas (knowledge, sociodemographic, social support, attitude to health care).

Summary, Conclusions and Implications for Future Research

This study was an attempt to explain differences in stage of diagnosis of colorectal cancer patients using a multiple causation model and utilizing multivariate statistical techniques to evaluate the contribution of each of six types of potential influence on the dependent variable. Of six types of variables included in the model, demographic variables and attitudes to health care did not seem to assist in explaining the differences. In the single area analysis, social support and knowledge (particularly knowledge specific to this disease) were able to some extent, explain potential factors contributing to a late stage diagnosis. The two areas which were helpful in single area analysis, and remained important in the full model analysis were health threat (attribution of cause of symptoms) and health care system variables (primarily number of visits to family doctor).

The results from this study confirm the results from the other recent study which also used patient interview data and looked specifically at factors associated with an "undesirable" outcome in colorectal cancer (McArthur and Smith, 1984). McArthur and Smith used delay as their dependent variable, but in their study, delay was significantly associated with stage of disease. Variables which were significant in McArthur and Smith's study were social support (advice from network member was associated with reduced time from first noticing a symptom to consulting a physician), health care system (if patient was examined by physician at first visit, time to referral was shorter), and health threat (patients whose initial symptom was abdominal pain or vomiting went more quickly to the doctor). Although the specific items within each area in the present study and in McArthur and Smith's study were not exactly the same, it is notable that in both studies these three general areas were important. McArthur and Smith (1984) did not report on any measure of knowledge, which was statistically significant in the univariate analysis in the present study; or on attitudes to health care. In their study, as in the present one, demographic factors were not associated with an undesirable outcome.

A multivariate model is instructive in looking at this problem. It is clear that several of the areas of Cummings Illness Behaviour Model are helpful in explaining stage of disease, and that using a multivariate analysis provides somewhat different results than one using only a single type of variable. A multifactorial approach is often used in

epidemiological studies done to help explain the etiology of cancer, and it appears it is also a useful approach to explain the events which happen once cancer occurs.

Implications for Future Research

Several salient points with regards to future research are highlighted by this attempt to explain why colorectal cancer patients are diagnosed late. Points which should be considered for future research are:

1. The biology of the tumor may have a larger role to play in determining stage of diagnosis, and deserves a closer look. The author is left with a sense that the nature of symptoms is important in getting one to an early diagnosis, but that symptoms may not be related to stage of disease, but perhaps to location of tumor in the bowel. Is it possible that tumors in certain locations cause symptoms while in other locations they do not? If a very early tumor causes symptoms severe enough to cause one to go to emergency, that patient may have a better chance of being treated early. Early cases had more emergency visits in this study.
2. Several areas from Cummings' model deserve a more detailed examination. Because this was in many ways an exploratory study, trying to determine, which, if any of the six areas were helpful in predicting stage of disease, it was not possible to look in great detail at all of them. As health threat and health care system variables were the two that remained important in this study in the full model

logistic regression, they should be investigated in more detail. It would be very helpful to have a valid and reliable instrument to record the perceived impact of symptoms on patients. This was a weak area of the present study.

3. There were many suggestions in this study that coexisting medical conditions may contribute to a late diagnosis by diverting both the patient's and physicians' efforts to dealing with another plausible (or real) diagnoses. Information on coexisting illness could be validated in future studies. The evidence from this study is suggestive only. It also would have been instructive to know whether patients were at higher risk for colon cancer, and if they were, whether they were being followed on a regular basis by their physician.

4. The whole area of attitudes to cancer is very interesting. It is well known that the attitudes to cancer are fairly pessimistic (Canadian Cancer Society, 1986). Is it possible that if one is able to acknowledge the possibility of getting cancer, that this helps ensure an early diagnosis? If this were the case, it would have important implications for public education programs. Further studies are needed to determine the meaning of the observation in this study and others, of the tendency of early patients to call their problem "cancer" and of late stage patients to call it something else. None of the studies quoted, or this one, have looked directly at this issue, but rather have made this observation in the context of looking primarily at something else.

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APPENDIX I

ACTUARIAL SURVIVAL RATES FOR COLORECTAL CANCER
PATIENTS IN ALBERTA*

	A N=346	B N=1488	C N=1069	D N= 361	NS N=1464
1 year	93%	89%	76%	35%	53%
2 years	91	80	55	12	41
3 years	84	72	44	5	33
4 years	80	65	37	4	29

* Includes patients diagnosed since 1977 in Alberta.

* Significant difference $p < .001$. Lee-Desu Statistic, SPSS

Source: Alberta Cancer Registry, 1985.

APPENDIX II

INFORMATION SHEET FOR PATIENTS

I am a graduate student in the Department of Community Health Science at the University of Calgary. I am currently carrying out a study of the experiences and responses of cancer patients to their illness. I'd like to tell you about the study and ask if I may call you in a few days time to ask if you would be willing to participate in my research.

What is the study?

The study is examining how people understand illness and react to it. Some of the factors that I am interested in are : symptoms and how a person reacts to them; how a person feels about doctors and health care; what people know and believe about illness; and what influence family and friends have on reactions to illness.

What does being in the study involve?

If you agree to be in the study, I would come to your home when it is convenient to you, and ask you several questions related to the topics above. This would take approximately one hour.

Why have you been chosen for the study?

Patients with a similar diagnosis have been chosen to be in the study. I hope to talk to as many of these people as possible so that I get a good overall picture of how these patients react to symptoms and

illness.

Will participation in the study affect your treatment?

Your decision to participate or not to participate will not affect your treatment or care in any way.

What happens to the information that will be collected?

All information will be kept strictly confidential. The results will be used in scientific presentations and publications, but the information will never be presented in such a way that individuals could be identified. Names will not be entered on any computer file and questionnaires will be destroyed when the study is completed.

Of what use is this study?

Hopefully, studies like this will help us understand what patients experience when they become ill, and provide better health care.

If you would like further information, please feel free to call me:

Judy Birdsell

Home: 244-0113 University: 220-7369 (This is the graduate student office at the University.
If I am not there, please leave your name and number, and I will call you back.)

APPENDIX III

Consent Form

I, _____, agree to be interviewed by Judy Birdsell for the purposes of the study of factors associated with ill health. I understand that the interview will be about one hour in length and will include questions about my symptoms, my visits to the doctor, and my family and friends.

I understand that I may stop at any time, or decide not to answer certain questions. I also understand that my decision not to take part in the study, or not to answer certain questions, will not affect my medical treatment or care in any way.

The results of this study will be used in scientific presentations and publications, but they will never be presented in such a way that individuals could be identified. All information collected will be kept strictly confidential and names will not be entered in any computer file.

After the study is completed, the questionnaire will be destroyed.

Date: _____ Signed: _____