

A study in general practice of the symptoms and delay patterns in the diagnosis of gastrointestinal cancer

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SUMMARY. Gastrointestinal cancer was classified into four groups according to the site: stomach, caecum and ascending and transverse colon, sigmoid colon and rectum. The incidence of these cancers in general practice is as rare as three per 10,000 consultations. I report on a study in general practice of the symptoms and delays in diagnosis in 150 patients with gastrointestinal cancer. There was an interval of many weeks between the onset of symptoms and diagnosis in the majority of cases. In approximately 50 per cent of cases there was an interval of weeks between the patient consulting the general practitioner and being referred for hospital investigation. No association was demonstrated between delay and social class, age, physical isolation, or the regular consulting rate of the patient. There was evidence that the consulting rate of some patients with gastrointestinal cancer increased in the 12 months before diagnosis because of the presence of symptoms not specific to the gastrointestinal tract.

Much more knowledge of the early symptoms of these cancers is required if the general practitioner is to be able to identify those patients with a high probability of early cancer from others who have symptoms which are common both to non life-threatening conditions and to cancer lesions.

Introduction

THE five-year survival rates for patients with gastrointestinal cancer have not improved significantly over the past 20 years despite advances in diagnostic and surgical techniques (Holland and Frei, 1973; Waterhouse, 1974). It is not known whether the survival rate could be improved if early symptoms were investigated more intensively, as little is known of the symptoma-

tology of early gastrointestinal cancer (Lim *et al.*, 1974). In Japan, mucosal and sub-mucosal gastric cancers have been detected in asymptomatic patients using contrast methods, cytological and endoscopy screening techniques. A significant improvement in survival rate has been achieved in such cases (Rubin, 1974). These findings have been confirmed by Elster and colleagues (1975) in West Germany. If the survival rate in Great Britain is to be improved it is important to know if mucosal and sub-mucosal gastrointestinal cancers commonly produce symptoms, and which symptom clusters are significant. It is also important to know where delay in diagnosis occurs (Hodgkin, 1973).

Aims

This study examines:

1. The symptoms which were presented to the general practitioner in patients with cancer of the stomach, caecum and ascending and transverse colon, sigmoid colon, and rectum.
2. The time elapsing before a diagnosis of gastrointestinal cancer was made was divided into:
 - a) The time between the patient's realization that something was wrong and reporting it to the general practitioner.
 - b) The time between the patient consulting the general practitioner and being referred to hospital.
 - c) The time between contact with the hospital (that is, date of referral) and a definite diagnosis being made.

Method

Eight general surgeons working in three hospitals in Leeds gave permission for any patient admitted under their care with gastrointestinal cancer to be invited to take part in the study. An interviewer visited the patients on the ward as soon after admission as possible, when nursing staff considered the patient well enough to be approached. The patients were invited to consent to be asked simple questions about their illness, and for

their general practitioner and hospital doctor to give the interviewer details of the illness.

Questionnaire and type of information

The age, sex, marital status, occupation of patient or spouse, and whether or not the patient lived alone were recorded. The patient was asked about the frequency of consultation with his or her general practitioner during the five years before the present illness, and in particular about the frequency of consultation for any reason in the 12 months before the present illness began.

The patients were asked about the following symptoms: loss of energy or unusual tiredness, loss of appetite or nausea, vomiting, vomiting blood, abdominal pain or discomfort, changes in bowel habit, blood in motions, loss of weight, and other symptoms. The interviewer enquired how long each symptom had been present. As this was a retrospective study, the patient was asked for the earliest possible time it was thought the symptoms had occurred and the latest time of onset, the mean of these two recollections being recorded.

After the patient had been interviewed, the hospital records were examined and the general practitioner seen by appointment. The following information was obtained from each source:

1. The date of referral to hospital by the general practitioner.
2. The symptoms which were recorded in the notes at hospital and by the general practitioner.
3. The date of definite diagnosis by microscopy.
4. Histology findings, either from biopsy or after surgical removal of the cancer. Only patients with cancer proven by histology were accepted into this series.

When the general practitioner was interviewed, he was asked how often the patient had consulted him in the 12 months before the onset of the symptoms thought to be due to the gastrointestinal cancer. He was asked to compare this consulting rate with the average consulting rate per year by that patient during the previous five years. At no time did the interviewer have direct access to the general practitioner records.

Co-operation achieved during the study

Of 154 patients who were approached to take part in the study, 150 consented. These patients were in the care of 109 practitioners, of whom one refused to be interviewed and three others were unable to help when interviewed. Not all patients had general practitioners, and of those who had, a few had never consulted them or could not answer questions about how often they consulted their doctor.

Of the 150 patients in the study there was inadequate information from general practitioners in 17 cases, inadequate information from the patient in five cases, and no general practitioner records in four cases. Infor-

mation about consulting rates was available from general practitioner records for the five years before gastrointestinal cancer symptoms developed in 124 cases.

Use of information obtained

From the three sources of information the time of onset of each symptom was obtained, and the time recorded in weeks:

1. Before those symptoms were reported to the general practitioner.
2. Between the first report to the general practitioner and referral to hospital.
3. Between initial referral by the general practitioner and definite diagnosis by microscopy (a period which includes any waiting period for a hospital appointment as well as the consultations and investigations carried out at hospital).

Where there was a difference in the date given by the patient, general practitioner, and hospital records, the earliest date was taken either from the patient's recall of events or the general practitioner record. Such differences were not common and if the later date had been selected the findings in this study would not have been significantly different. (Details are available.)

Symptoms

Patients were grouped according to the site of the neoplasm:

1. Stomach.
2. Caecum, ascending colon, transverse colon.
3. Sigmoid colon.
4. Rectum.

The symptoms occurring in the four groups of patients with malignancies at the different sites of the gastrointestinal tract were separated into:

1. Those symptoms which were reported to the general practitioner before he decided to refer to hospital.

Table 1. Time elapsing between onset of symptoms and diagnosis of gastrointestinal cancer in 150 patients.

Number of patients = 150	Mean interval (weeks)	
1. Before diagnosis was made	25	
2. Between onset of symptom and reporting to general practitioner	9	Range = one week to over two years
3. Between patient consulting general practitioner and being referred to hospital	10	
4. Between date of referral to hospital and histological diagnosis	6	

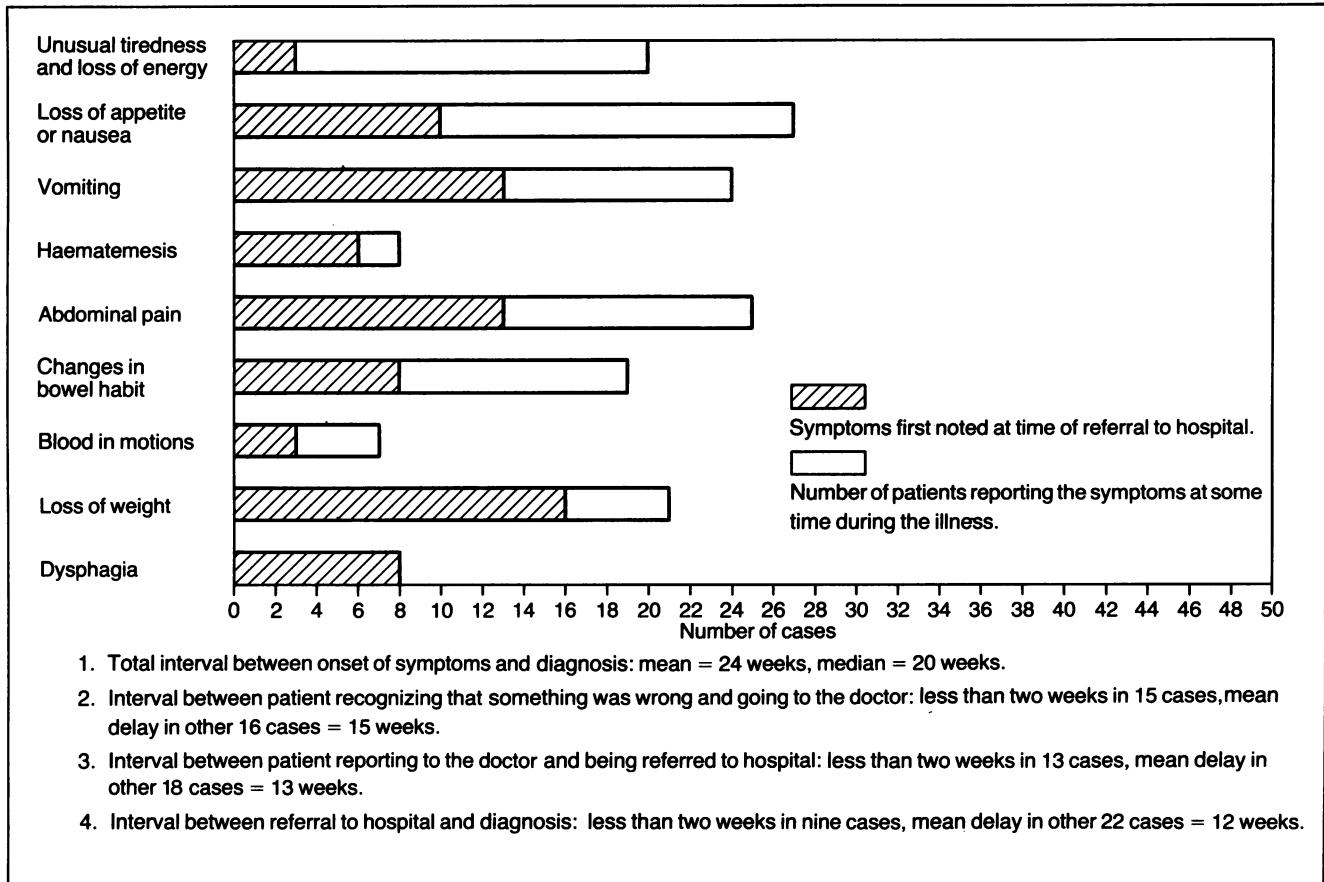


Figure 1. Symptoms of carcinoma of stomach (n = 31).

2. Those symptoms which were first recorded by the general practitioner on the day when he decided referral to hospital was indicated.

Results

The time elapsing before diagnosis was made histologically in all types of gastrointestinal cancer in this study is shown in Table 1.

The symptoms discussed here are those which the general practitioner selected to record. The absence of a symptom does not mean that it was not reported by the patient, but only that it was not recorded, and it is probable that in recording the general practitioner selected symptoms which seemed dominant or important rather than being comprehensively descriptive of all that the patient said. In Figures 1 to 4 the recorded symptoms arising from the different sites of carcinoma are shown, and the hatched areas indicate when that symptom was associated with the general practitioner making an immediate referral to hospital. In this study it was found that in only one instance did the general practitioner arrange for radiological investigation before referring the patient to a hospital physician or surgeon. At the time of this study in Leeds a general practitioner was able to request a barium meal but no other contrast radiography, and the interval before the

investigation was completed might be a few weeks. The large majority of patients in this series were referred direct to surgeons. Investigations, such as blood counts, ESR, and occult blood tests, might have been requested by general practitioners before referral to hospital, but this information was not requested.

The footnotes to each figure show the intervals of time which occurred before a diagnosis was made after the patient had recognized that something was wrong. This time is subdivided into the time that passed owing to patient delay in reporting to the doctor, the time that passed before the general practitioner referred to hospital after the patient had first consulted him, and that which passed after the patient had been referred to hospital.

Consulting rates

An analysis of the 127 records available showed that in 23 patients (18 per cent) there was an increased consulting rate in the 12 months before the onset of symptoms which were regarded by the general practitioner as related to the final diagnosis. This increased rate was obtained by comparing it with the consulting rate per year of the particular patient during the previous five years. The increased rate was not due to screening tests initiated by the general practitioners.

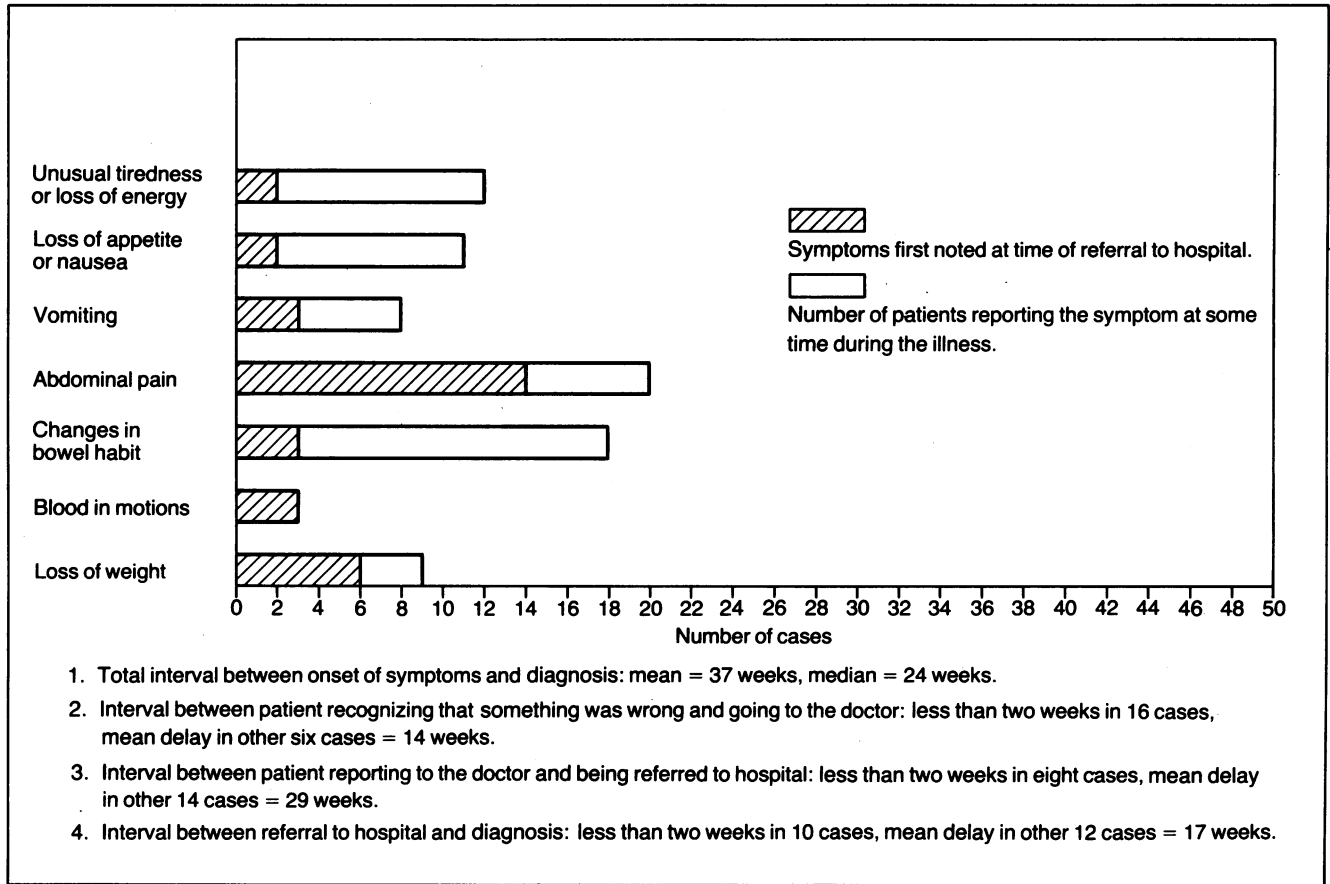
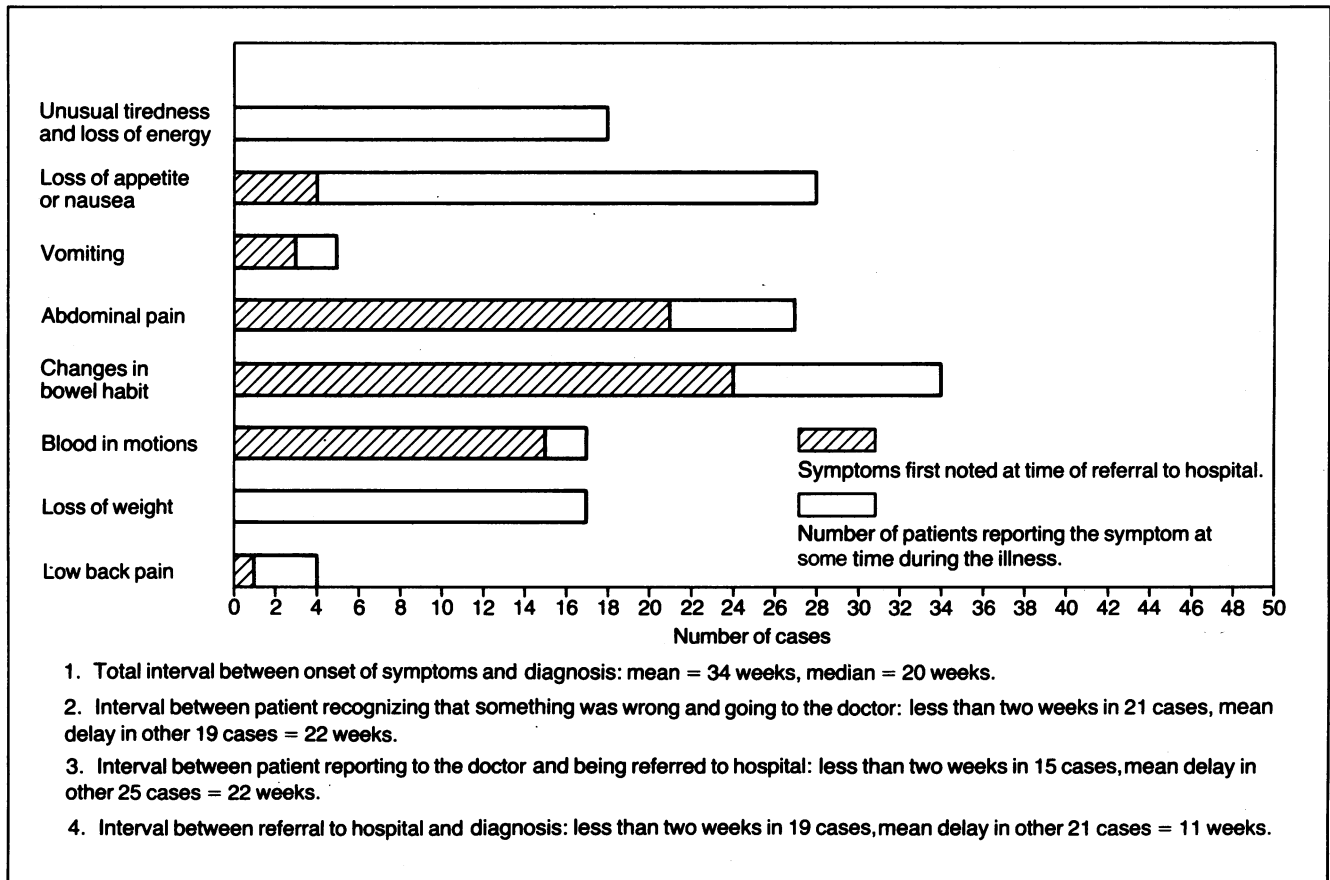


Figure 2. Symptoms of carcinoma of caecum and ascending and transverse colon (n = 22).

Figure 3. Symptoms of carcinoma of sigmoid colon (n = 40).



Delay and its relation to socio-economic class, age, and isolation

There was no significant difference in the socio-economic class, age, or social isolation of those patients who experienced delay compared with those who experienced no delay in referral. (Figures can be supplied on request.)

Discussion

It is possible that the information from general practitioner records in this study is inadequate owing to failure of the general practitioner to make records of consultations. There is also likely to be considerable selectivity in what the general practitioner records. What has been established is that a consultation occurred and that a date was entered on a record even though few symptoms may have been recorded. If a general practitioner failed to make any record then this would have tended to reduce the number of weeks elapsing between symptoms first being reported to the general practitioner and referral to hospital. It is impossible to exclude this error but patients might be expected to recall situations where they have frequently consulted their doctor before being referred to hospital. Whilst there is no way of checking this retrospectively, Table 2 shows the patient recall of frequency of con-

sultation with their general practitioner compared with the doctor's recorded consulting rates.

These figures show that patients frequently underestimated their consulting rate when compared with the rate noted by the general practitioner.

Such a finding suggests that inadequate record keeping is not likely to distort grossly the delays which are reported in this study when they occur between a patient first going to the general practitioner and a referral being made to hospital. The close correlation between the differences in consulting rates during a period of 12 months and five years as recalled by the patient compared with the doctor's record suggests some consistency, despite the impossibility of validating such a retrospective study.

Symptoms and diagnosis

In analysing the early symptoms of gastrointestinal cancer a distinction is necessary between those which occur singly and those which are clustered into symptom patterns. No attempt has been made here to examine the doctor's selectivity in recording symptoms, or the probability that symptom clusters are more significant than symptoms in isolation. In Figures 1 to 4, the association of symptoms is not indicated and the non-specific symptoms, like tiredness and loss of weight or appetite, may have preceded or been presented at the same time

Figure 4. *Symptoms of carcinoma of rectum (n = 57).*

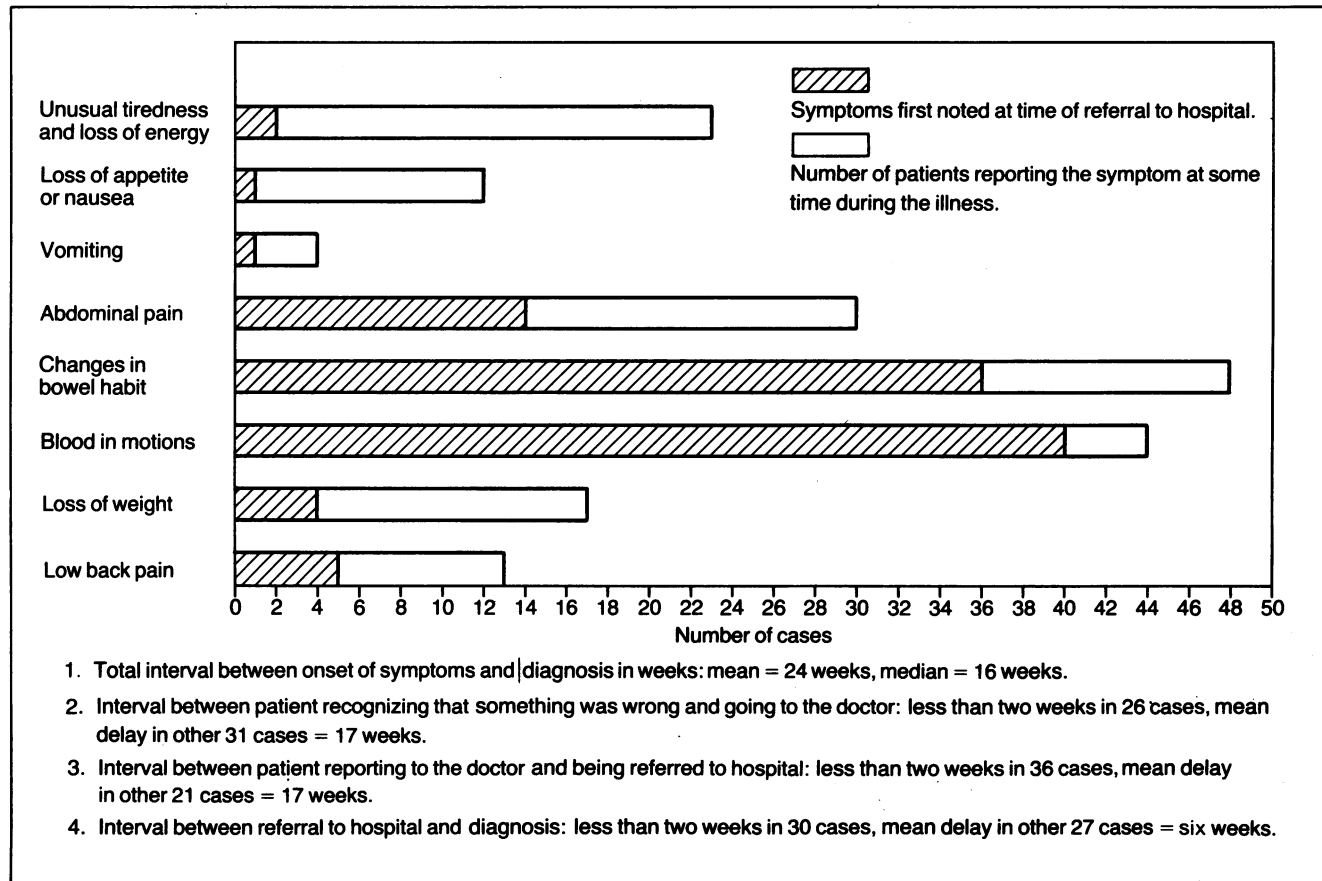


Table 2. A comparison between patients' recalled consulting rate and the general practitioner's recorded consulting rate.

	Patients' recall compared with general practitioner records		
	Less than general practitioner	Same as general practitioner	More than general practitioner
For five years before present illness	38	76	10
In 12 months before present illness	37	73	14

as the more indicative symptoms such as pain, blood in motions, dysphagia, or haematemesis. Horrocks and de Dombal (1975) have shown the accuracy of diagnosis on symptom data using a digital computer. This work was done in a surgical outpatient clinic where the patients had already been selected by the general practitioner. A similar approach using a computer might help the general practitioner to select symptom clusters indicative of disease and requiring further hospital investigation. Nevertheless, in almost 50 per cent of cases there was immediate referral to hospital by the general practitioner when the patient first reported symptoms.

The histograms of the recorded symptoms (Figures 1 to 4) illustrate the difficulty for the general practitioner in selecting at first presentation those patients with serious pathology. Symptoms such as tiredness, loss of appetite, and vomiting occur frequently when no life-threatening underlying pathology is present.

Those patients with bleeding and pain were likely to be referred to hospital with the least delay. If it could be shown that one or two symptoms presenting together to the general practitioner in certain age/sex groups were associated with a high probability of serious disease, then the delay in diagnosis might be reduced. Such knowledge of indicative symptoms might also answer the question of whether or not early gastrointestinal cancer is frequently symptomatic or asymptomatic; it would also help in educating patients to recognize those symptoms which require immediate medical advice.

Delay in patient reporting symptoms to the doctor

Further studies are required to correlate early diagnosis after symptoms have developed with survival, and it is not known whether or not early diagnosis, dependent on symptoms, affects the prognosis. It has yet to be shown that there is benefit to be gained by making the diagnosis as early as possible after symptoms have developed. If this benefit is assumed, then the challenge to health education is to indicate to patients those symptoms which should be reported immediately to the doctor. This is not just a matter of knowledge as patient

fears, denials, and expectations will influence the decision to be taken. In almost 50 per cent of cases in this study many weeks elapsed between the patient realizing that "something was wrong" to the time when the patient consulted a doctor. Patient education must follow the doctor first being convinced of the value of early diagnosis of symptoms, and secondly knowing which symptoms or groups of symptoms are indicative of serious disease. It may be that presymptomatic screening by endoscopy and cytology is the only way of improving survival rates from gastrointestinal cancer.

Delay between the patient reporting symptoms to the general practitioner and being referred to hospital

Those patients who delay before reporting symptoms to the general practitioner may be referred immediately to hospital when the first consultation occurs. Conversely those patients who report early to the general practitioner may suffer delay before being referred.

The findings of this survey do not reveal any correlation between age, sex, social status, or normal frequency of doctor/patient contact, and the delay before a patient is referred to hospital. Inevitably a general practitioner sees few new cases of gastrointestinal cancer in a year, and it is easier to allocate resources to those parts of the health service where diseases are concentrated—the acute medical and surgical wards of hospitals—rather than to the community where early diagnosis may lead to cure. By the time such concentration has been achieved this study shows that many weeks may have elapsed since symptoms first started. The delays in diagnosis are often due to patient delay in reporting to the general practitioner and to delay at hospital after referral has been made, but the longest delays occur when the general practitioner does not recognize the potentially serious nature of the patient's condition.

Pereira Gray (1966) made a comprehensive analysis of the role of the general practitioner in the early detection of malignant disease. He indicated the need for a retrospective analysis of cases of cancer such as has been attempted here, and he indicated reasons for delays in diagnosis in addition to the three discussed in this paper. He also considered the time elapsing before treatment was started and included patients diagnosed radiologically.

I have discussed only cases where the diagnosis was made histologically and where surgical treatment was given. A retrospective study of the delays in diagnosis, which includes all cases of gastrointestinal cancer, is necessary to determine whether the patterns of delay differ in those patients receiving surgery, compared with those patients who have gastrointestinal cancer at death, but who never have surgery. It is possible that when there is more delay the neoplasm has become so widespread by the time diagnosis is made that surgery is not

attempted. Such further studies would need to include patients seen by consultant physicians at hospital.

Increasing the technical skill of hospital diagnosis and surgery is very expensive and probably has a strictly limited benefit unless ways can be found of achieving early detection of cancer at the primary care stage. A general practitioner with a list size of 2,500 patients can expect to see 200 to 250 patients per year with new episodes of gastrointestinal symptoms (OPCS *et al.*, 1974). The symptoms of tiredness and loss of appetite will occur even more frequently. It is important for the general practitioner to analyse and select accurately those patients who require the sophisticated technology of a modern hospital. Indeed, the computer potential which is seen dramatically in the images produced by the 'whole body scanner' can appropriately be applied to analysing the vast number of variables which confront a general practitioner listening to a patient's symptoms. The small desk-top computers now available make detailed research into symptoms possible, and it would be a mistake to consider the use of computers in general practice only in terms of data storage.

Conclusion

I have investigated one aspect of clinical research in general practice, the analysis of symptoms, which requires exploration with adequate resources. Perhaps the most important question is: "Does early treatment, once symptoms have developed, lead to increased life expectancy?" To concentrate research into cancer cure in the hospital is not only very expensive but in terms of benefit to the patient may be extremely wasteful. By comparison, research into the selection of patients who should appropriately and quickly be seen at hospital promises to be cost effective.

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Acknowledgements

The interviewing was done by Mrs Valerie Lazenby, whose work is acknowledged with much appreciation. This study would not have been possible without Miss K. Edwards' secretarial work. The co-operation of the following surgeons: Professor G. R. Giles, Professor J. C. Goligher, Mr T. G. Brennan, Mr D. B. Feather, Mr G. Hill, Mr R. C. Kester, Mr D. Pratt, and Mr G. Wilson, over 100 general practitioners, and the patients and hospital records staff in Leeds is recognized with thanks. The advice of Professor I. D. G. Richards, Dr M. W. Sutcliffe, and Dr H. J. Wright was also a great help.

Academic medicine threatened

The need for critical scientific appraisal of the things doctors are doing grows with the advance of modern medicine. Without an academic presence the equilibrium between the practising clinician and external pressures (of which the commercial interests of the pharmaceutical industry are only one) will inevitably be destroyed. In the face of a substantial threat that they may be forgotten in the current maelstrom, academic clinical staff need to emphasize the part they play not only in the teaching but also in the critical examination and maintenance of medical care.

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Pharmacologic closure of patent ductus arteriosus in the premature infant

The prostaglandins affect smooth-muscle tone of the ductus arteriosus. Patent ductus often complicates the clinical course of prematurely born infants with respiratory-distress syndrome. In the present study, a single oral or rectal dose of a potent inhibitor of prostaglandin synthesis, indomethacin, was administered to six consecutive premature infants with the syndrome who would otherwise have undergone surgical ligation of the patent ductus. Within 24 hours all the clinical symptoms and physical, echocardiographic and radiographic signs attributable to substantial left-to-right shunting through a patent ductus arteriosus dramatically and permanently disappeared. A transient reduction in renal function was observed in two infants in whom sustained ill-effects did not occur. The observation that constriction and closure of the patent ductus arteriosus may be induced pharmacologically raises important possibilities for the improved treatment of the respiratory-distress syndrome.

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