Diagnostic delay in neoplastic disease

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SUMMARY. It may be possible to measure quality of care in general practice by selecting a single criterion of care such as the delay in the recognition of neoplastic disease. Seven general practitioners reported on 55 new cases and the results are analysed according to age, sex, and diagnostic category. An attempt is made to quantify 'quality' by comparing the theoretical 'ideal' delay (retrospectively assessed) with the 'actual' delay. The wider implications of the study are discussed.

Introduction

IN 1974/75 a group of general practitioners met to discuss the philosophy and practicality of 'medical audit'. A project was mounted to test some of the ideas arising from their discussions. The objective was to try to measure one index of medical care in general practice. The parameter selected had to be regarded as important by all of the participating doctors and all agreed that new cases of neoplastic disease fulfilled this criterion. The assumption was made that if diagnostic delay could be reduced in this group of patients, then the quality of care could reasonably be considered to have been improved.

The first step would be to quantify the delay, the second to analyse the reasons why delay occurred, and the third step (which would be beyond the scope of this study) to reduce or eliminate it completely. It was realized that diagnostic delay would be significantly greater with some types of growth, but the small size of the study would not permit the matching of cases by diagnostic category.

An early and important observation was that in comparing an individual doctor's performance with that of his colleagues, judgement could usefully be made only by the doctor openly discussing his results and comparing them with those of his colleagues.

However, in order to measure one's own level of performance as a percentage of the 'ideal' it was necessary to establish an index, for "by providing an index we can use man's natural drive to evaluate his performance in relation to others" (Hodgkin, 1973).

Method

An observation record card entitled "Assessment Sheet for all New Cases of Neoplasia" was constructed which would include all new cases that presented between 1 March 1975 and 28 February 1976. Only the minimum information about patients was recorded, such as age, sex, occupation, and diagnosis. The date of onset of symptoms or signs, whichever was the earlier, was recorded and the date of the first presentation to the general practitioner. The difference between these two dates in days was taken as the delay attributable to the patient.

The date on which the diagnosis was made was noted and the number of days between the first presentation to the general practitioner and the establishment of the diagnosis was regarded as the delay due to the system (that is, general practitioner plus diagnostic services plus specialist services). An estimate was then made by the general practitioner when, in retrospect, the diagnosis could have been made had ideal conditions prevailed. The comparison between 'actual' delay and the 'ideal' delay (retrospectively assessed) would indicate the amount of improvement possible. The reason for the delay was also recorded so that the numerical quantification would not stand in isolation as the only criterion for comparison. Furthermore, by describing the reason for the delay, practical suggestions for subsequent system improvement would be more likely to arise.

Seven general practitioners took part in the survey, but as some were in partnership with others who were not taking part, the population at risk (about 30,000) could not be accurately determined.

The number of doctors directing cases into the survey

Table 1. Age/sex analysis.

Sex	Not stated	Male	Female	Total
Age in years				
<15	—	1	1	2
16 to 30	—	—	1	1
31 to 45	—	—	1	1
46 to 60	—	6	6	12
>61	—	15	22	37
Not stated	1	—	1	2
Total	1	22	32	55

Table 2. Analysis of diagnostic categories.

Diagnostic group		Male	Female	Total
Gastro-intestinal				
Oesophagus	(1)	2	1	4
Stomach		3	4	7
Caecum/colon		2	3	5
Rectum/rectosigmoid		1	2	3
Gastro-intestinal tract (part not specified)		1	—	1
Bronchus/lung		5	1	6
Breast		—	4	4
Bladder		2	1	3
Carcinomatosis primary unknown		1	—	1
Uterus				
Body		—	2	2
Cervix		—	3	3
Other				
Kidney		—	1	16
Right tonsil		—	1	
Pancreas		1	—	
Meningioma		—	1	
Left vocal cord		1	—	
Hodgkin's		—	1	
Carcinoma of thyroid		—	1	
Osteogenic sarcoma		1	1	
Epidermal carcinoma		—	1	
Acute leukaemia		1	—	
Chronic lymphatic leukaemia		—	1	
Mixed parotid tumours		—	2	
Rodent ulcer		1	—	
Melanoma of anus		—	1	
Total	(1)	22	32	55

through the seven participating general practitioners was about 15.

Results

A total of 55 cases (22 male, 32 female) were recorded during the twelve-month period. One form submitted did not indicate the patient's age or sex, and another form omitted the age of the patient.

The age distribution of the cases is tabulated in Table 1 and the diagnostic categories listed in Table 2.

After examining the reasons given for the diagnostic delay, a simple list of the points at which delay could occur was compiled (Table 3). Some of the reasons given under "Patient Delay" highlighted the difficulty in assessing accurately how great a part this played in total delay.

Table 3. Causes of diagnostic delay.

1. Patient delay

The estimate of delay depends on:
- Patient's memory
- Patient's willingness to admit to any delay

The delay itself may be due to:
- Fear or ignorance of symptoms
- The 'effort' to go to the doctor
- A fatalistic attitude that early action will not influence outcome

2. System delay

Before consultation with general practitioner (appointment system or crowded waiting rooms, distance from patient's home or work, etc.)

After consultation with general practitioner:
- Failure to recognize symptoms or suspect diagnosis
- Failure to pursue the diagnostic suspicion because of coexisting disease or social reasons
- Failure to send referral letters (i.e. administrative errors)

At hospital:
- Failure to send appointment
- Length of waiting time
- Failure to recognize the significant signs or symptoms
- Failure to pursue diagnosis because of coexisting disease or social reasons
- Delay at secondary referral (e.g. for diagnostic x-ray, endoscopy or biopsy)

Patients may opt out of the process at any stage. The reason for opting out may be attributed to either patient or system failure or both.

Table 4 tabulates the delay in days and shows the following:

Delay due to the patient	(x)
Delay due to the system	(y)
Total delay	(x + y)

The retrospective delay (R) is the delay that the patient's general practitioner assessed was the earliest possible date that a diagnosis could have been made had the ideal conditions prevailed. The possibilities for the size of R are listed in the code to Table 4.

Table 5 is an attempt to express as a percentage the extent to which the system delay could be improved.

Tables 4 and 5 show only the first 36 cases since this number was thought enough to illustrate the theoretical issues raised which are discussed in the respective codes to the tables.

Discussion

General standards of care

The search for higher standards of care is fundamental to the discipline of medicine. It is the *raison d'être* for

Table 4. Analysis of consultation to show retrospective delay (R).

Patient	Patient delay (days) x	System delay (days) y	x+y	Retrospective delay (days) R	R greater than zero	y−R	R=0
1	0	237	237	58	✓	179	
2	0	45	45	45	✓	0	
3	28	41	69	13	✓	28	
4	7	78	85	37	✓	41	
5	21	120	141	95	✓	25	
6	35	0	35	0		0	✓
7	3 years	3 years(?)	6 years	3 years	✓	0	
8	6	20	26	20	✓	0	
9	301	?	301+(?)	301	✓	?	
10	0	0	0	?	✓	?	?
11	10	30	40	?30	?	?0	
12	2	1	3	0		1	✓
13	21	0	21	0		0	✓
14	4	0	4	0		0	✓
15	0	2	2	?	?	?	
16	1	0	1	?	?	?	?
17	183	84	267	84	✓	0	
18	183	184	367	?	?	?	
19	?	65	65+(?)	6	✓	59	
20	7	49	56	10	✓	39	
21	60	21	81	21	✓	0	
22	35	38	73	38	✓	0	
23	21	0	21	21	✓	−21*	
24	5	20	25	?	?	?	
25	?	40	40+(?)	0		40	✓
26	3	39	42	0		39	✓
27	5 years	0	5 years	0		0	✓
28	0	59	59	13	✓	46	
29	0	275	275	275	✓	0	
30	0	?21	?21	?	?	?	
31	0	115	115	6	✓	109	
32	7	19	26	26	✓	−7*	
33	?	42	42+(?)	?	?	?	
34	10	0	10	?	?	?	
35	14	106	120	106	✓	0	
36	2	23	25	23	✓	0	

Code to Table 4

y−R=0 if:

(i) system delay could in retrospect have been avoided totally or

(ii) if there was no system delay at all and no patient delay

* The minus sign indicated that the diagnosis would have been made earlier had the patient presented earlier.

Column 1: Patient delay =x days
Column 2: System delay =y days
Column 3: Total delay =x+y days
Column 4: Retrospective delay =R days

Possibilities with regard to the size of R:

(i) R cannot be greater than x+y (if it is then the general practitioner's conception of retrospective assessment will be incorrect).

(ii) R can be greater than x or y.

(iii) If R is greater than y (this means if the patient presented earlier) the diagnosis could have been made earlier assuming that the system was working to maximum efficiency.

Column 5: If R is greater than zero there is some system failure or patient failure.

Column 6: y−R indicates the amount of delay that is likely to be encountered after the patient presents to the general practitioner.

Column 7: If R equals zero then there is no system delay or patient delay.

the professional organizations and the Royal Colleges (*Lancet*, 1972).

The measurement and quantification of these standards is now well established (Donabedian, 1966; Eisele, 1967; McWhinney, 1972) but its application to general practice is a more recent development (Acheson, 1975; Williams, 1975; Stevens, 1977). The bibliography has been recently comprehensively reviewed in the 1976 Butterworth Gold Medal Essay (Stevens, 1977).

Table 5. Possible improvements in system delay.

Patient	System delay	Theoretically least possible delay as a percentage of actual system delay: $\frac{y-R}{y}$ per cent		Contribution of system delay to total diagnostic delay: $\frac{y}{x+y}$ per cent	
1		*75.5*		*100*	
2		*0*		*100*	
3		*68.0*		*59.4*	
4		*52.6*		*91.8*	
5		*20.8*		*85.1*	
6	No delay	*0*	(y=0)	*0*	(y=0)
7	3 year delay	*0*	(y=R)	*50*	
8	20 day delay	*0*	(y=R)	*76.9*	
9	Insufficient data	?		?	
10					
11		*0*	(y=R)	*75.0*	
12		*100*	(R=0)	*33.3*	
13	No delay	*0*	(y=0)	*0*	(y=0)
14		*0*	(y=0)	*0*	(y=0)
15	Insufficient data	?		*100*	
16	Insufficient data	?		*0*	(y=0)
17	84 days delay	*0*	(y=R)	*31.5*	
18	Insufficient data	?		*50.0*	
19		*90.8*		?	(insufficient data)
20		*79.6*		*87.5*	
21	21 days delay	*0*	(y=R)	*25.9*	
22	38 days delay	*0*	(y=R)	*52.1*	
23	Patient delay	*0*	(y=0, R=+21)	*0*	
24	Insufficient data	?		*80*	
25		*100*	(R=0)	?	
26		*100*	(R=0)	*92.9*	
27	Patient delay	*0*	(R=0, y=0)	*0*	
28		*78*		*100*	(x=0)
29	275 days delay	*0*	(y=R)	*100*	(x=0)
30	Insufficient data	?		?	
31		*94.8*		*100*	*(x=0)*
32	Patient delay	—	(y=19)	*73.0*	
33	Insufficient data	?	(R=26)	?	
34	Insufficient data	?		*0*	(y=0)
35	106 days delay	*0*	(y=R)	*88.3*	
36	23 days delay	*0*	(y=R)	*92.0*	

Code to Table 5

In an attempt to measure the contribution of system delay to total diagnostic delay, y can be expressed as a percentage of x+y, that is,

$$\frac{y}{x+y} \times 100 \text{ per cent}$$

In an attempt to measure the degree to which system delay can be improved, the theoretically least possible delay (which has been retrospectively assessed) can be expressed as a percentage of actual system delay incurred, that is,

$$\frac{y-R}{y} \times 100 \text{ per cent}$$

In this equation 100 per cent means that the theoretical delay equals the actual delay, that is, no improvement is possible. Anything less than 100 per cent indicates improvement in the system should be possible.

It may be that some diagnostic groups, or patient groups, or doctors may consistently fall into, or perform at, particular percentage levels and if this could be shown, it would be worthy of further study.

Again, any percentage figure calculated shows the percentage of system delay in relation to total delay, and is thus a measure of the amount of improvement that could take place.

Actual numbers of days delay would, however, probably make for better comparison than these percentage figures.

In the equation

$$\frac{y}{x+y} \text{ per cent,}$$

if x=0, that is, there is no patient delay, then the equation will equal 100 per cent and this means that all the delay is due to system delay. If y=0, that is, there is no system delay, then the equation will equal zero. In the equation

$$\frac{y-R}{y} \text{ per cent,}$$

if y=R then the equation will equal zero. This conceals the actual quantity of diagnostic delay which in percentage terms is zero per cent, indicating room for 100 per cent system improvement. Assessing retrospectively R as equal to y may indicate real deficiencies in the system, or a general practitioner who is hypercritical either of himself, or of the system, or of both.

If R=0 then y−R=100 per cent if y is not also equal to zero. Thus a less critical retrospective assessment will produce figures nearer 100 per cent—and "a perfect general practitioner and a perfect system" will also do the same.

Standard of care for malignant disease

McQueen Thompson (1958) in Australia gave one of the first accounts by a general practitioner of the systematic detection of malignant disease. In Britain the problem of diagnostic delay of malignant disease in general practice was first fully considered by Pereira Gray (1966/1967) in the 1966 Hunterian Society Gold Medal Essay. His classification of patient delay differs from that illustrated in Table 3 by indicating the points at which the patient opts out of the system, whereas Table 3 is more of an indicator of the 'why' of patient delay, rather than the 'how'. Pereira Gray's detailed narrative on system delay emphasizes and agrees with the headings as set out in the second section of Table 3.

The method used in this study was designed specifically to look at diagnostic delay in all new cases of neoplastic disease. Hodgkin (1973) described a system of "Delay Pattern Analysis" for use in his practice to measure delay in all diagnostic categories. His system, whilst comprehensive, would be difficult to apply to a large number of general practitioners working in separate practice premises because of the administrative and analytical problems. However, a recallable, simplified assessment sheet was successfully applied to a variety of practices and practitioners and it has the theoretical advantage that it could form the basis for a more extensive study, involving not only patients and their family doctors but the hospital specialists through whose beds most cases of malignancy pass.

During the survey several poorly thought out features became evident. First, the confirmation of the date of diagnosis was not clearly defined. The diagnostic dates should be listed in four separate stages:

1. Date of clinical suspicion.
2. Date of clinical confirmation.
3. Date of radiological or biochemical confirmation.
4. Date of histological proof.

This would remove some of the confusion which was experienced in completing the "date on which the diagnosis was first made".

A further fault was the failure to define clearly which cases should be included in the survey year. Should those cases be included whose diagnosis was made during this year when symptoms may well have begun before the observation period? They were, in fact, but the status of those cases whose signs and symptoms started during the period of the observation but whose confirmatory diagnosis was made only after 28 February 1976, was not satisfactorily clarified. There was only one such case and it was included.

One doctor submitted an assessment sheet for a patient with a recurrence of a tumour and this was excluded since only new cases were being observed. However, the problem of inclusion of a very late recurrence of malignancy, or the appearance of a second malignancy would have to be carefully considered in any long-term extension of this study.

Retrospective assessment of the date on which the diagnosis should have been made could be criticized as being subjective and therefore liable to inaccuracy. The retrospective assessment will, of course, depend upon a value judgement of the doctor but the general practitioner is well placed to make this subjective assessment reasonably, for it is the general practitioner who initiates, or fails to initiate, the diagnostic system after the patient has presented to him.

With a more complex observation card tailored to different diagnostic groups of neoplasia, it would be possible to record accurately the date of onset of a variety of specific signs and symptoms which would in retrospect be the first indicator of disease. This would be an improvement on the loosely defined retrospective assessment used in this survey.

The explanations for the diagnostic delay were considered to be entirely reasonable in most cases and not unreasonable in many others.

If Tables 4 and 5 are looked at in isolation from the detailed explanations then over 25 per cent of cases could have been diagnosed earlier, and the delays, in one case of 179 days, could well have led to harsh criticism.

The interpretation of the tables is related to the pressures of clinical practice, but even so it appears that there is room for improvement. I doubt whether the objective of the study, namely to use the assessment of diagnostic delay in neoplastic disease as a measure of quality of care, has been achieved, but there is no doubt that during the year in question the participating doctors experienced an increased index of suspicion for new cases of cancer.

I hope that a larger and more sophisticated survey can be mounted based on this 'pilot' study. Its task would certainly be easier if it confined itself to considering the diagnostic delay in different groups of neoplasia, and the reasons for that delay, rather than attempting to measure the total quality of care.

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