

Occasional report

Effect of information leaflets on knowledge in patients with gastrointestinal diseases

G M HAWKEY AND C J HAWKEY

From the Department of Therapeutics, University Hospital, Nottingham

SUMMARY Twelve patient information leaflets concerning common gastrointestinal diseases were produced by the British Digestive Foundation and evaluated to determine whether patients knew more about their disease if they received a leaflet. Eleven hundred and fifty patients attending gastroenterology clinics in the United Kingdom were assessed by postal questionnaire of whom half had received a leaflet relevant to their diagnosis six weeks before assessment. Seven hundred and fifty one replied (398 leafleted, 353 non-leafleted). Most patients found the leaflets helpful and easy to understand; few found them worrying. They were regarded as a better source of information than doctors, particularly for information about the characteristics of the illness and side effects of treatment. In all diagnostic groups assessed the patients' knowledge of their disease was significantly greater if they had received a leaflet than if they had not. Individual responses by patients without leaflets showed that fundamental misconceptions persisted about digestive diseases. The British Digestive Foundation leaflets are an effective means of imparting disease related information to patients.

Communication between doctors and patients is often inadequate.¹⁻¹² Information is better retained if given in writing^{13,14} and recently information leaflets have become popular.¹⁵⁻²³ They satisfy and please patients^{8,15-20,22,23} and influence behaviour^{17,21} although inadequacies are common.^{9,10,18,19,22,23} Written information as package inserts to accompany prescribed medicines have received particular attention as there is clear evidence that patients are poorly informed by traditional methods.^{10,12,15,16,18,19} In a survey in Southampton, 62% of patients felt they did not get enough information about drugs.¹² Twenty five per cent of those taking penicillin and 45% of those taking a non-steroidal anti-inflammatory drug did not know its name.¹⁰ In a population survey 73% of those currently taking medication were not aware of any potential side effects.¹² In a small short term study, package inserts accompanying prescribed medicines led to a high level of satisfaction, a greater number of patients able to name the drug they were

taking and a greater awareness of adverse drug effects, when assessed 4 to 10 days after receipt.¹⁶

There has been little evaluation of disease related leaflets. In 1987 the British Digestive Foundation, in association with the British Society of Gastroenterology launched a major series of 12 patient information leaflets covering common areas of gastroenterology. The primary aim was to increase knowledge rather than to influence behaviour. This study was carried out to assess whether patients knew more about their disease after receiving a leaflet.

Methods

Seventeen members of the British Society of Gastroenterology were invited to write leaflets on topics of widespread gastrointestinal interest, in their area of expertise. They were asked to write between 1000 and 2500 words and to cover areas where patients have requested information,^{9,10,18,22} including pathophysiology, symptoms, complications, impact on lifestyle, prognosis, treatment, and side effects. The authors were specifically asked to use short words and sentences, and to be factual rather than patronis-

Address for correspondence: Dr C J Hawkey, Dept of Therapeutics, University Hospital, Queen's Medical Centre, Nottingham NG7 2UH.

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Table 1 Details of the leaflets

| | Patient assessments | | | | |
|-----------------------------------|---------------------|------------------|-----------------------|---------|----------|
| | Length (words) | Reading ease* | Easy to understand | Helpful | Worrying |
| Will it affect my gut? | 1962 | 56 | - | - | - |
| Hiatus hernia and heartburn | 1479 | 63 | 89% | 80% | 16% |
| Peptic ulcer | 1376 | 64 | 92% | 87% | 5% |
| Coeliac disease | 1683 | 65 | 100% | 83% | 0 |
| Diarrhoea and constipation | 2587 | 62 | 92% | 75% | 13% |
| Inflammatory bowel disease | 2499 | 66 | 90% | 92% | 3% |
| Diverticular disease | 815 | 46 | 78% | 84% | 11% |
| Polyps and cancer of the colon | 1187 | 70 | - | - | - |
| Irritable bowel syndrome | 1403 | 58 | 85% | 85% | 9% |
| Liver disease | 1702 | 69 | 86% | 92% | 30% |
| Gall stones | 1444 | 74 | 93% | 89% | 10% |
| Having an endoscopy | 2045 | 52 | - | - | - |

*Reading ease score of 60-65=accessible to the 75% of population with IQ \geq 90; a higher score indicates easier to read: - = not tested.

ing or didactic. After a process of amalgamation and editing the series was reduced to 12 leaflets covering the topics listed in Table 1. During the editing process, sentences were shortened and words simplified with the aim of achieving a reading ease score greater than 50 but without reducing the information content. The reading ease score was calculated by the method of Fleisch²¹ using the formula:

$$\text{reading ease} = 206.84 - 0.85W - 1.02S$$

where W = number of syllables per 100 words
S = average sentence length in words.

Line diagrams to a maximum of 25 were included to aid understanding. Each leaflet also included definitions of 63 terms commonly used in gastroenterology as well as information about the British Digestive Foundation, an invitation to contribute to its research funds, a Deed of Covenant, and a Bankers' Order.

The final versions were made into A5 size booklets 16-24 pages in length using two tone printing. Seven hundred thousand leaflets were printed with the support of Thomas Morson Pharmaceuticals and distributed in packs to a medical and/or surgical gastroenterologist at each major teaching or district general hospital in the United Kingdom.

ASSESSMENT

Members of the British Society of Gastroenterology were invited to help in the assessment of leaflets. Twenty four volunteers were selected to cover major regions of England and Wales and include a reason-

ably balanced mix of medical and surgical units in teaching and district general hospitals. These centres receive leaflets three months in advance of other centres.

PATIENT ENROLMENT

Patients in the waiting room before medical consultation were given a written invitation to participate in a 'digestive disease survey' of their experiences and views. The doctor entered the name, address, and diagnosis on an accession form of patients giving their informed consent. The card also instructed the doctor whether or not to give the relevant leaflet to the patient. This was done at the end of the consultation and the doctor was instructed to avoid introducing an association between the leaflet and the digestive disease survey. The accession lists were mailed to a central office and questionnaires sent to all patients, on average six weeks after the patient's initial consultation.

QUESTIONNAIRES

The questionnaires contained nine questions about life style and 12 about the patients' experiences in attending general practitioners and hospitals with their gastrointestinal disease, with particular reference to information given at each stage. They were asked that if they had ever read a leaflet to answer nine questions about its value and information content. All patients were asked to identify any organisations they knew funding research in digestive diseases, whether they were in favour of public donations to digestive disease research, and whether they had made a donation themselves. They were asked to select correct definitions for 10 medical terms from a list of 24. Ten points were awarded for a correct and 10 points deducted for an incorrect answer (maximum possible 100, score for random response 0).

Within each questionnaire there were 20 factual questions related to the patient's declared diagnosis. These required a yes/no response. The correct answers were yes and no in equal numbers. The sense of all these questions was reversed for half the patients to avoid a positive response bias. These factual questions were scored +5 correct, -5 incorrect, and 0 (don't know) and a total factual mark computed (maximum possible score 100, score for random response 0).

Non-factual questions were asked in two forms, with positive responses first for half of them and negative responses first for the other half. This order of response was also reversed for each question in half the questionnaires to avoid a positive response bias. Patients who did not complete and return their questionnaires received no further prompting.

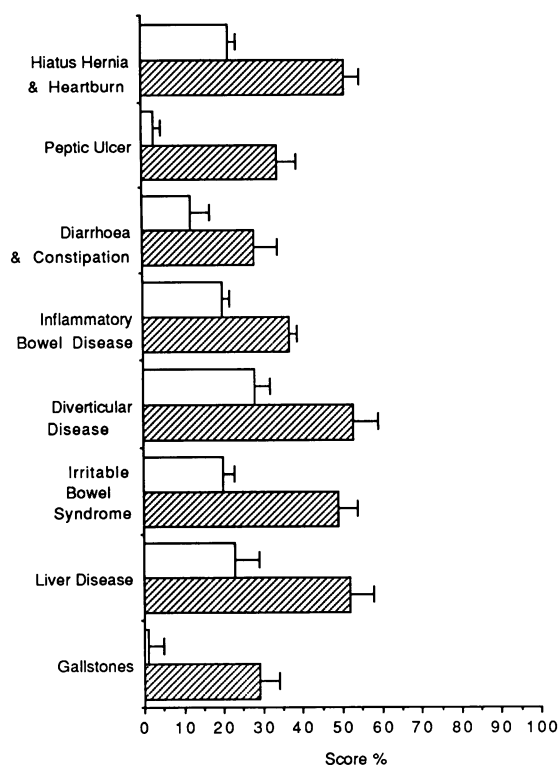


Figure Scores on the factual questionnaire for patients receiving leaflets (hatched bars) compared to controls (open bars). Means and SEM are shown. Improvements in leafleted patients are highly significant in each category.

STATISTICAL ANALYSIS

Data were analysed using the SPSSX program. Differences in proportions were assessed using the χ^2 test. The significance of influences on factual scores was analysed by analysis of variance. Differences between leafleted and non-leafleted patients in specific disease groups were analysed by unpaired *t* tests. Data are quoted as means and SEM.

Results

READABILITY

Details of the leaflets are shown in Table 1. In all but one instance the target readability score was achieved and for most the score was over 60, making them easily accessible to those with an IQ of 90 or greater (approximately 75% of the population).

PATIENT RESPONSE TO QUESTIONNAIRE

Seven hundred and fifty one of the 1150 patients who were sent questionnaires returned them satisfactorily completed (response rate 65%, without prompting).

Table 2 Details of patients replying to the questionnaire

| | Not leafleted | Leafleted |
|--|---------------|-------------|
| Age* | 49.3 (18.3) | 48.2 (17.0) |
| Sex† (M/F) | 160/188 | 191/202 |
| Social class 1-2 | 21.1% | 20.8% |
| 3-4 | 39.0% | 38.9% |
| 5-6 | 8.3% | 7.8% |
| Retired, unemployed, unclassified | 31.6% | 32.5% |
| Teaching hospital/district general hospital† | 178/166 | 193/194 |
| Medical/surgical‡ | 261/73 | 286/89 |

*Mean (and standard deviation) †Total number do not aggregate to 751, reflecting a small number of missing data.

CHARACTERISTICS OF THE PATIENTS ASSESSED

The characteristics of patients who received leaflets were similar to those who did not (Table 2). There were similar numbers attending teaching hospitals and district general hospitals, but more in medical than surgical clinics reflecting current gastroenterological practice in the United Kingdom. The largest number of patients were those with inflammatory bowel disease reflecting the prevalence of such patients in follow up gastroenterology clinics.

PATIENT ASSESSMENT OF THE LEAFLETS

Patients assessed the leaflets on scales containing five points (two positive, two negative, one neutral) for ease of understanding and overall helpfulness of information. The proportions expressing positive views ('very', 'fairly') are shown in Table 1. In a similar five point scale patients were asked how worrying or reassuring it was to read the leaflets. The proportions of patients who rated their leaflet as very or fairly worrying is shown in Table 1. Most patients found the leaflet easy to understand and helpful and few declared themselves worried by their content.

PATIENTS' SOURCE OF INFORMATION

Patients checked a 5 point scale ('too much', 'every-

Table 3 Satisfaction with sources of information

| Satisfactory information about | From | | |
|----------------------------------|----------------------|-----------------|---------|
| | General practitioner | Hospital doctor | Leaflet |
| Illness | 37% | 69%† | 81%‡‡ |
| Investigations | 48% | 70%† | 67%† |
| Reasons for doing investigations | 40% | 67%† | 69%† |
| Treatment | 46% | 71%† | 71%† |
| Side effects of treatment | 16% | 28%† | 46%‡‡ |
| Desirable changes in lifestyle | 34% | 43%* | 49%† |

* $p < 0.05$ compared with general practitioner; † $p < 0.01$ compared with general practitioner; ‡ $p < 0.05$ compared with hospital doctor.

thing necessary', 'quite a lot', 'only a bit', 'nothing') quantifying the adequacy of information from their general practitioner, hospital doctor, or leaflet if they received one. Few patients checked 'too much' and Table 3 shows the percentage of those remaining who gave positive responses ('everything necessary' or 'quite a lot'). The data concerning general practice and hospital doctors did not vary significantly between recipients and non-recipients of leaflets. The data show that the hospital doctors were perceived as being a significantly better source of information than general practitioners for all aspects of the patient's illness. The leaflets were perceived as being significantly better than the hospital doctors about the characteristics of the illness and about the side effects of treatment.

KNOWLEDGE

Initially factual scores were analysed by multivariate analysis of variance using class, type of patient (medical/surgical), type of hospital (teaching/district general hospital), disease category and whether the leaflet was given or not, as possible determining variables. This analysis showed that scores were influenced by diagnosis ($f=8.12$, $p<0.01$), class ($f=5.38$, $p<0.01$), and type of hospital attended ($f=6.09$, $p=0.014$) but the strongest determinant was receipt of a leaflet ($f=160.7$, $p<<0.001$).

Average scores achieved by recipients and non-

recipients of leaflets in individual disease categories, where at least 25 patients were assessed, are shown in the Figure. Responses by patients with peptic ulcers and gall stones who did not receive leaflets were not significantly different from a random response rate. Scores in non-leafleted patients with other conditions were somewhat higher but the highest score for non leafleted group (diverticular disease) was lower than the lowest score for a leafleted group (gall stones). Direct comparison showed that scores achieved by leafleted patients were significantly higher (unpaired t test, $p<0.01$ for all) than control patients for each of the eight diagnoses investigated. Patients who received leaflets could also define gastroenterological terms better than those who did not. (Score 44 (2) v 14 (2), $p<0.001$.)

AREAS OF KNOWLEDGE AND MISCONCEPTION

The control patients who did not receive leaflets consistently scored well on some questions and badly on others. Table 4 illustrates all questions where more than 50% of all patients questioned gave the correct answer (areas of knowledge). Table 5 shows common misconceptions (questions where those answering gave more wrong answers than right answers).

INFLUENCE OF LEAFLET ON BEHAVIOUR

There was some evidence that patients understood the implications for their lifestyle of the information contained in the leaflets. Thus, 40% of smokers with peptic ulcers declared the leaflet to have influenced them to stop in contrast with only 6% of patients with ulcerative colitis. All coeliac patients not taking a gluten free diet said they were more likely to take one as a result of the leaflets. Fibre consumption was common in all groups (38% claimed to eat a high fibre diet), but a further 29% of peptic ulcer patients were influenced to take a high fibre diet, reflecting a discussion of its possible benefits in duodenal ulceration in the leaflet.

KNOWLEDGE OF DIGESTIVE DISEASES

ORGANISATIONS

Twenty four per cent of patients who received a British Digestive Foundation leaflet were able to name an organisation connected with digestive diseases, compared with only 8% of those who had never received a leaflet. Eleven per cent of leafleted patients named the British Digestive Foundation, compared with none of the non-leafleted patients.

DONATIONS

Nine and eight per cent respectively of leafleted and non-leafleted patients claimed to have given money to a digestive diseases organisation, but only two

Table 4 *Specific areas of knowledge*

Most control patients knew that:

Heartburn

- 1 Heartburn does not arise in the heart
- 2 Heartburn can occur without a hiatus hernia
- 3 Heartburn is caused by reflux of gastric juice

Peptic ulcer

- 1 Ulcers can heal spontaneously
- 2 Smoking retards ulcer healing
- 3 About 1/4 of the population have an ulcer at some stage of their life
- 4 Iron makes the stools dark grey
- 5 Tarry stools can indicate bleeding

Inflammatory bowel disease

- 1 Sulphasalazine reduces relapse rates in ulcerative colitis by 1/4
- 2 Crohn's disease can affect any part of the gut
- 3 People with ulcerative colitis do not have primary abnormalities of personality

Irritable bowel syndrome

- 1 A syndrome is a collection of symptoms
- 2 The irritable bowel syndrome is not caused by smoking
- 3 There is an increased incidence of anxiety and depression in irritable bowel syndrome
- 4 Milk does not relieve bowel spasm

Gall stones

- 1 Most gall stones in the UK are formed from cholesterol
- 2 Women form gall stones more commonly than men

Table 5 *Specific misconceptions**Most control patients believed that:***Heartburn**

- 1 A hiatus hernia causes a bulge on the abdomen
- 2 Paracetamol irritates the oesophagus
- 3 Heartburn is not affected by weight loss

Peptic ulcer

- 1 Ulcers are most common in business men
- 2 People with gastric ulcers make too much acid
- 3 Duodenal ulcers are caused by stress at work
- 4 Two glasses of wine per day will retard ulcer healing
- 5 A bland diet will accelerate ulcer healing
- 6 If an ulcer is described as chronic it means it is very bad

Inflammatory bowel disease

- 1 Most patients with ulcerative colitis are smokers
- 2 Ulcerative colitis can involve the whole gut
- 3 Ulcerative colitis and Crohn's disease do not run in families

Irritable bowel syndrome

- 1 Only 1% of the UK population get irritable bowel syndrome symptoms
- 2 In the irritable bowel syndrome the bowel looks inflamed
- 3 95% of cases of irritable bowel syndrome will respond to a high fibre diet

Gall stones

- 1 Most gall stones form in the bile duct
- 2 Gall stones usually cause symptoms
- 3 Gall stone pain is nearly always in or over the gall bladder
- 4 Most people with gall stones need to take a low fat diet
- 5 Nearly all gall stone patients will need an operation

patients (0.5% of leafleted patients) had given to the British Digestive Foundation.

Discussion

Fundamental misconceptions about digestive diseases are widespread amongst British patients suffering from these diseases. For example, most of those with heartburn believe that a hiatus hernia causes a bulge on the abdomen whereas ulcer patients still perceive their disease as stress related, common in businessmen and requiring a bland diet. Similarly, patients with ulcerative colitis associate the disease with smoking, believe it involves the whole gut and does not run in families despite personal evidence to the contrary. Patients with gall stones do not know that they are common and usually asymptomatic. These and other misconceptions, reflected in low factual scores in non-leafleted patients show that there is a need for additional sources of information in British patients with gastrointestinal diseases.

Our data show that patients found the British Digestive Foundation leaflets easy to understand. The Fleisch readability score was to some extent predictive: one of the two leaflets which was not specifically edited to achieve high readability had the lowest readability score and was the hardest to understand. Most patients found the leaflets helpful

and relatively few found them worrying. That patients could find worrying information helpful is illustrated by the leaflet on liver disease which was perceived both as most helpful (together with that on inflammatory bowel disease) and most worrying.

As a source of information hospital doctors were perceived as better than general practitioners, perhaps partly reflecting the fact that diagnoses are less likely to be evident when a general practitioner is consulted. Leaflets were perceived as being as good or better than hospital doctors as a source of information, and better than general practitioners, even though doctors can offer individualised information whereas leaflets cannot. The perceived performance of doctors was least satisfactory in relation to information about side effects of treatment and desirable changes in life style. Whilst leaflets were generally a better source of such information, our data show that patients want still more information in these areas. Side effects of treatment may be better covered by prescription package inserts but future disease related leaflets should include more information on desirable changes in lifestyle.

Our primary aim was to increase patients' knowledge of their disease and this was achieved as patients who received leaflets scored significantly better in all the disease categories tested. This was true even in the leaflets with low readability scores which were reported as harder to understand. Our patients were studied much longer after receipt of the leaflet (six to eight weeks) than in the previous study of prescription package inserts, where the interval was only four to 10 days.¹⁶

One of our secondary aims was to increase awareness of the British Digestive Foundation. In this respect, the leaflets were a moderate success raising the number of patients able to name the British Digestive Foundation from 0 to 11%. This did not have any significant effect, however, on patient donations to the British Digestive Foundation.

Influencing patient behaviour was not in itself a primary aim. The philosophy motivating production of the leaflets was to reduce rather than increase patients' dependence on the medical profession. Moreover, previous leaflets which have been written specifically to influence patient behaviour have not always been effective. Cigarette consumption can be influenced at least in the short term,²¹ but longterm drug compliance is not,¹⁷ and use of graphic instructions for the collection of mid-stream specimens of urine has been detrimental.²⁵ The limited data on behaviour included in our survey suggest that patients understood the significance of what they read and came to rational conclusions – for example, peptic ulcer patients who smoked were influenced to stop whereas those with ulcerative colitis were not.

We conclude that the British Digestive Foundation leaflets informed patients who read them. Patients found them helpful and often regarded them as a better source of information than doctors.

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