

# A comparison of irritable bowel syndrome patients managed in primary and secondary care: the Episode IBS study

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## SUMMARY

**Background:** It is thought that people with irritable bowel syndrome (IBS) who consult secondary care have more severe symptomatology than those treated mainly in primary care.

**Aims:** To describe the physical and psychological symptoms of IBS, and the health-related quality of life of patients managed in primary and secondary care.

**Design of study:** Cross-sectional observational survey.

**Setting:** The general population of the United Kingdom (UK).

**Methods:** A cohort of people with IBS symptoms was recruited via a UK-wide newspaper advertisement. Frequency, duration and severity of symptoms, and health-related quality of life data were collected by semi-structured telephone interviews. Descriptive analysis allowed the comparison of those managed in primary care with those consulting secondary care. Logistic regression was used to identify factors associated with patients consulting secondary care.

**Results:** Data on 486 participants with confirmed IBS (Rome II criteria) were examined. Similar patterns in symptom severity were found in primary and secondary care groups. Factors associated with IBS patients consulting secondary care were: male sex, a longer length of time since diagnosis, having frequent bowel motions, not having dyspepsia in the past 3 months, and having used medication and alternative therapies. Although patients managed in secondary care have greater impairment to their usual activities, both groups had similar health-related quality-of-life profiles.

**Conclusion:** High levels of physical and psychological morbidity were present in population-based volunteers managed in both primary and secondary care. This study suggests that patients with IBS managed solely in primary care are affected as much as those attending secondary care.

**Keywords:** health care seeking behaviour; irritable bowel syndrome; quality of life; referral and consultation.

## Introduction

IRRITABLE bowel syndrome (IBS) is one of the most common gastrointestinal disorders and can account for up to 50% of referrals to gastroenterology outpatient clinics in the United Kingdom (UK).<sup>1</sup> Between 10 and 15% of the general population may have IBS, and it affects women more than men.<sup>2</sup> However, it is estimated that only 10% of people with irritable bowel syndrome seek medical advice and most of those who do are managed in primary care.<sup>3</sup> Those who consult secondary care report more severe gastrointestinal symptoms and increased levels of psychological disturbance compared with those who do not. Therefore, pain severity as well as psychological distress may, in part, explain healthcare-seeking behaviour.<sup>4</sup> In the UK, less than one-fifth of patients are referred to hospital specialists, usually because of uncertainty about the diagnosis or an unsatisfied patient.<sup>5</sup>

IBS symptoms, such as abdominal pain, distension, and altered bowel function, exist in a continuum described as 'mild to severe'. IBS can also give rise to a wide variety of non-colonic symptoms, such as dyspepsia, lethargy, backache, and urinary symptoms, all in the absence of demonstrable pathology. Little is known of the pathophysiology of IBS and, as a consequence, medical treatment is often ineffective.<sup>6</sup> Psychological interventions, such as gut-directed hypnotherapy and biofeedback, although promising, are not yet standard treatments for IBS.<sup>7</sup>

To concentrate on only the physical symptoms of IBS would limit understanding of the full complexity of this chronic condition, and would underestimate the burden of IBS on an individual's quality of life and on society.<sup>8</sup> IBS negatively affects general health, vitality, social functioning, bodily pain, diet, sexual function, and sleep, and is associated with time lost from work.<sup>9</sup>

Most quality-of-life studies involve refractory subsets of IBS patients in secondary care, or have relied on retrospective or short-term prospective information about the effects of symptoms on daily living.<sup>9</sup> Little is known about 'healthy' people in the community with IBS or with IBS symptoms, many of whom do not seek medical advice. It is generally thought that people who do not seek medical attention or who are managed in primary care have less severe IBS symptomatology and less psychosocial morbidity than those patients managed at specialist centres, but this assumption is based upon limited research.<sup>10</sup> The aim of this study is to explore and describe IBS symptoms, including health-related quality of life, and healthcare utilisation in population-based individuals and compare them with those who have consulted secondary care.

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**HOW THIS FITS IN***What do we know?*

It is generally thought that the more severe cases of irritable bowel syndrome (IBS) are referred to secondary care.

*What does this paper add?*

This study shows that patients with IBS managed in primary care are affected as much as those attending secondary care.

**Invitation to Irritable Bowel Syndrome Sufferers**

The *Episode* survey is designed to improve our understanding of how IBS affects the daily lives of people in the community. If you are aged 18 years or over and have been diagnosed with IBS, you are invited to take part in this 6-month postal survey being conducted by researchers at the Western General Hospital, Edinburgh.

To find out more about this national research project please call:  
Freephone 0800 \*\*\* \*\*\*\*

**No medication or examinations are involved**

Box 1. *Episode* newspaper advertisement.

**Methods**

A cross-sectional study, 'Episode', was designed to examine the frequency, duration, and severity of symptoms in a cohort of population-based people with IBS symptoms. Participants were recruited via a UK national newspaper advertisement (Box 1), which appeared in both broadsheet and tabloid newspapers. Ethical approval for the study was obtained from the Lothian Ethics Committee and all participants gave written consent. A research nurse screened individuals who responded to the advertisements via a semi-structured telephone interview to confirm inclusion criteria and eligibility (Rome II criteria)<sup>11</sup> for the study. Inclusion criteria are shown in Box 2. A combination of the presence and frequency of each IBS symptom allowed classification of each volunteer as an IBS case or IBS non-case based upon Rome II criteria.

After establishing eligibility into the study, the research nurse continued with the semi-structured telephone interview, collecting information from each participant. Data on participants' demographics, medical histories, and their symptoms and severity of IBS were recorded. Participants were also asked if they had ever seen a hospital doctor for their IBS symptoms, establishing if the volunteer was managed in primary care or had consulted secondary care for

Study subjects must fulfil the following eligibility criteria:

- Aged 18 years or over
- Diagnosed with irritable bowel syndrome (IBS) by a medical practitioner
- History of bowel symptoms consistent with Rome II criteria for IBS on the basis of constant or recurrent abdominal pain or discomfort that has at least two of the following features: (a) relieved with defecation or (b) onset associated with a change in stool frequency or (c) onset associated with a change in stool form
- IBS symptoms experienced within the last 3 months
- Absence of coexisting gastrointestinal diagnosis (that is, inflammatory bowel disease, coeliac disease, and cancer of the colon)
- Written consent to participate in the study, and willingness to complete a daily diary card for a period of 6 months

Box 2. Inclusion criteria for the *Episode* study.

Table 1. Characteristics of eligible subjects at baseline of *Episode* study.

Variable	Managed in primary care <sup>a</sup>	Seen in secondary care <sup>b</sup>	Total population <sup>c</sup>
Mean age in years (SD)	38.6 (16.0)	40.9 (16.4)	40.1 (16.3)
Women	37.9 (16.0)	40.4 (17.1)	39.5 (16.7)
Men	48.2 (11.9)	42.6 (13.8)	43.5 (13.6)
Sex (n [%])			
Female	156 (93)	250 (79)	406 (84)
Male	12 (7)	68 (21)	80 (16)
Married (n [%])	95 (57)	190 (60)	285 (59)
Ethnic group (n [%])			
Caucasian	140 (86)	252 (86)	392 (86)
Non-caucasian	22 (14)	40 (14)	62 (14)
In full-time work (n [%])	83 (50)	168 (53)	251 (52)
Months since symptoms began (mean [SD])	7.9 (6.3)	10.5 (8.2)	9.6 (7.7)
Duration in months of symptoms to first diagnosis (mean [SD])	4.7 (4.6)	7.0 (5.9)	6.2 (5.6)

<sup>a</sup>(n = 168). <sup>b</sup>(n = 318). <sup>c</sup>(n = 486). SD = standard deviation.

their IBS. A sample (10%) of the volunteers recruited into the study had their diagnosis of IBS confirmed by directly contacting their general practitioner.

The impact of IBS on individuals' quality of life was examined using a generic measure of health status: the EuroQol with five domains (EQ-5D).<sup>13</sup> The validity and reliability of the EQ-5D has been established.<sup>14</sup> Because the EQ-5D contains only five questions, the research nurse could conveniently administer the questionnaire while conducting the telephone interview. The results of the EQ-5D were collated with the rest of the patient's data.

**Statistical analysis**

Individuals' characteristics were compared between those managed in primary care and those consulting secondary care. Continuous data were summarised by means and standard deviations, and categorical data were summarised as percentages. Logistic regression modelling was carried out to determine which factors were independently associated with referral to secondary care. All of the clinical and psychosocial variables of symptom scoring from the Rome II classification of dysfunctional gastrointestinal disorders were considered for inclusion in the model. Odds ratios (ORs) and confidence intervals (CIs) of individuals consulting secondary care are given for the variables

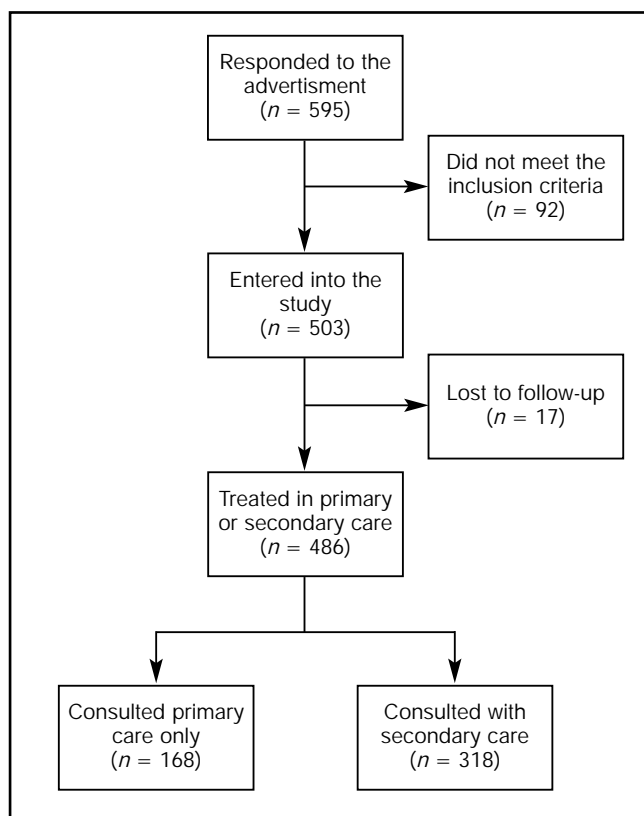


Figure 1. Diagram of subject inclusion into the Episode study.

included in the final logistic regression model. Statistical analysis was performed on STATA version 7.0.

## Results

Five hundred and three people were recruited into the study initially, but 17 were lost to follow-up (Figure 1). Therefore, 486 people (406 [84%] female, mean age = 40.1 years) were used in this analysis. From the telephone interview, it was determined whether the subjects were managed in primary care ( $n = 168$ ) or ever consulted secondary care ( $n = 318$ ). Table 1 gives the characteristics of these two groups.

Most of the study population was female, but relatively more men had been referred to secondary care for their IBS symptoms compared with women (85 versus 62%). Patients treated in secondary care had a longer duration of symptoms. The two groups were similar in age, marital status, work status, and race.

Table 2 gives the symptom patterns experienced at evaluation, such as the frequency of motions, stool consistency, pain description, and symptom duration. Table 2 also lists the physical symptoms that the participants observed in the 3 months prior to the study. We found that patients treated in secondary care used medication and alternative treatments more often than those managed solely in primary care (Table 3). The most popular alternative treatments used by the cohort were acupuncture, massage, hypnotherapy, exercise, and reflexology.

Results of the logistic regression modelling are presented in Table 4. The factors included in the final model are ind-

Table 2. Irritable bowel syndrome symptom description given by participants.

Symptom description	Managed in primary care <sup>a</sup> (n [%])	Seen in secondary care <sup>b</sup> (n [%])	Total population <sup>c</sup> (n [%])
Abdominal discomfort	164 (98)	307 (97)	471 (97)
Abnormally frequent motions	95 (57)	194 (61)	289 (59)
Abnormally infrequent motions	84 (50)	119 (37)	203 (42)
Abnormally mushy stools	95 (57)	189 (59)	284 (58)
Abnormally hard stools	68 (40)	122 (38)	190 (39)
Abdominal fullness	153 (91)	276 (87)	429 (88)
Urgency	108 (64)	225 (71)	333 (69)
Straining	92 (55)	164 (52)	256 (53)
Mucus	68 (41)	127 (40)	195 (40)
Other IBS symptoms	57 (34)	117 (37)	174 (36)
Abdominal pain			
Pain is relieved with motion	78 (47)	136 (43)	214 (44)
Pain with bowel problems	66 (40)	149 (47)	215 (44)
Neither	1 (1)	2 (1)	3 (1)
Both	22 (12)	31 (9)	53 (11)
Bowel disturbances			
Constipation	41 (24)	74 (23)	115 (24)
Diarrhoea	52 (31)	132 (42)	184 (38)
Both	74 (44)	106 (33)	180 (37)
Neither	1 (1)	6 (2)	7 (1)
Symptom duration in past 3 months			
Less than a day	28 (18)	54 (18)	82 (17)
1-2 days	46 (29)	69 (22)	115 (25)
3-4 days	28 (18)	67 (22)	95 (20)
5-7 days	15 (9)	32 (16)	47 (10)
8-14 days	12 (8)	9 (3)	21 (5)
More than 14 days	29 (18)	76 (25)	105 (23)
Other symptoms in the past 3 months			
Dyspepsia	133 (80)	203 (64)	336 (70)
Migraine	132 (79)	258 (81)	390 (80)
Depression	143 (85)	259 (82)	402 (83)
Anxiety	130 (77)	235 (74)	365 (75)
Backache	107 (64)	202 (64)	309 (64)
Other symptoms	109 (65)	185 (59)	294 (61)

<sup>a</sup>( $n = 168$ ). <sup>b</sup>( $n = 318$ ). <sup>c</sup>( $n = 486$ ).

ependently associated with consulting secondary care. The final model shows that men are much more likely than women to consult secondary care (OR = 3.33, 95% CI = 1.70 to 6.50). Also, individuals using medication for IBS in the past 3 months (OR = 1.68, 95% CI = 1.08 to 2.51) and using alternative therapies for the treatment of their IBS (OR = 2.01, 95% CI = 1.09 to 3.70) have increased odds of consulting secondary care. For each increase in time of 1 month since diagnosis with IBS (OR = 0.94, 95% CI = 0.89 to 0.97), having abnormally infrequent bowel motions (OR = 0.65, 95% CI = 0.43 to 0.97), and having symptoms of dyspepsia in the past 3 months (OR = 0.49, 95% CI = 0.31 to 0.79) are associated with decreased odds for consulting secondary care.

Table 3. Treatments taken by patients at or before the start of the survey.

Treatment taken by patient	Managed in primary care <sup>a</sup> (n [%])	Seen in secondary care <sup>b</sup> (n [%])	Total population <sup>c</sup> (n [%])
Currently taking medication	117 (70)	229 (72)	346 (71)
Taken medication previously	108 (64)	241 (76)	349 (72)
Adjustments to diet	132 (79)	259 (81)	391 (80)
Tried relaxation techniques	45 (27)	95 (30)	140 (29)
Tried alternative treatments	16 (9)	59 (19)	75 (15)

<sup>a</sup>(n = 168). <sup>b</sup>(n = 318). <sup>c</sup>(n = 486).

Participants were asked to describe their feelings about their IBS symptoms as part of the interview. Of those asked, 59% felt angry about having IBS 'often or sometimes', 22% felt this way 'always'. A majority (63%) felt less satisfied with life because of IBS and 70% felt 'fed up' with having IBS. No difference was observed in the prevalence of these feelings between those seen in secondary care and those managed in primary care.

The results for each of the five domains of the EQ-5D quality-of-life questionnaire are given in Table 5. Most people reported no problems with the mobility (85%), self-care (96%), and usual activities (70%) dimensions, but for the pain and discomfort dimension, most people reported some pain (68%). An equal number of people reported no or moderate for the anxiety and depression dimension. A difference between patients managed in primary care and secondary care was found for the usual activities dimension. More patients managed in secondary care reported some problems (32%) for usual activities, compared with those managed solely in primary care (21%). Evaluation of health-related quality of life of the IBS patients over time will be reported separately.

## Discussion

This study found that, irrespective of medical treatment for IBS in primary or secondary care, there is a considerable burden of disease in the population. This is evident from the self-reported symptom severity on disease-specific and generic quality-of-life measures. Factors identified by logistic regression to be independently associated with IBS patients consulting secondary care are as follows: male sex, a longer length of time since diagnosis, having frequent bowel motions, not having dyspepsia in the past 3 months, and more likely to have used medication and alternative therapies. Although these factors are statistically significant in the logistic regression model, it is evident that patients managed in primary care do not have less 'severe' symptoms of IBS. For example, patients with dyspepsia or abnormally infrequent bowel motions were found to be more likely to be managed solely in primary care, after adjusting for sex and the other factors included in the model.

Table 4. Factors independently associated with patients consulting secondary care.

Final logistic regression model	Odds ratio	95% CI	P-value
Sex			
Female	1.00 <sup>a</sup>		
Male	3.33	1.70 to 6.51	<0.001
Time since first diagnosed (increasing by 1 month)	0.94	0.89 to 0.97	0.001
Having frequent bowel motions	1.00 <sup>a</sup>		
Having abnormally infrequent bowel motions	0.65	0.43 to 0.97	0.001
Not using medication previously	1.00 <sup>a</sup>		
Using medication in the past 3 months	1.68	1.08 to 2.61	0.029
Using no alternative therapies	1.00 <sup>a</sup>		
Using alternative therapies	2.01	1.09 to 3.70	0.020
Not suffering from dyspepsia recently	1.00 <sup>a</sup>		
Having dyspepsia in the past 3 months	0.49	0.31 to 0.79	0.003

<sup>a</sup>Reference category.

Table 5. Health-related quality of life (EQ-5D).

Dimension of health	Managed in primary care <sup>a</sup> (n [%])	Seen in secondary care <sup>b</sup> (n [%])	Total population <sup>c</sup> (n [%])
Mobility			
No problem	142 (89)	252 (83)	394 (85)
Some problem	18 (11)	50 (17)	68 (15)
Self-care			
No problem	152 (96)	289 (96)	441 (96)
Some problem	7 (4)	13 (4)	20 (4)
Usual activities			
No problem	125 (78)	196 (65)	321 (70)
Some problem	33 (21)	98 (32)	131 (28)
Can not do usual activities	1 (1)	8 (3)	9 (2)
Pain and discomfort			
No pain	37 (23)	66 (22)	103 (22)
Some pain	106 (67)	204 (68)	310 (68)
Extreme pain	15 (10)	29 (10)	44 (10)
Anxiety and depression			
None	83 (53)	149 (50)	232 (50)
Moderate	73 (46)	142 (47)	215 (47)
Extreme	2 (1)	10 (3)	12 (3)

<sup>a</sup>(n = 168). <sup>b</sup>(n = 318). <sup>c</sup>(n = 486).

The Episode study recruited a large population of volunteers with confirmed diagnosis of IBS for an observational study. Rome II definitions were used because they are accepted worldwide for the study of IBS. The volunteers were self-selected and may not represent the overall population of IBS sufferers, and so our findings cannot be generalised because of possible selection bias. However, these results still have merit because they represent a population who are self-aware of their disease and willing to

identify themselves as having IBS. This study shows that there is a small IBS patient population who use primary care for the total management of their disease. Therefore, in recognising that the severity of disease is similar to those who consult secondary care, it is important that decision makers in primary care establish appropriate resources and training in general practice for the management of IBS.

Recent studies have attempted to determine the extent of IBS in the general population by random selection of people.<sup>14</sup> They do not, however, characterise the individuals beyond identification of symptoms. Mearin *et al* recruited an IBS sample group to represent the Spanish general population using home-based interviews to identify IBS subjects.<sup>16</sup> However, there is still a potential for selection bias using this method, with some people unwilling to participate. A large sample of patients obtained by other methods may also be impractical in time and perhaps unethical. With a large study enrolment without validation, many of the participants may not have a physician diagnosis of IBS, which may dilute the overall effect of the illness on NHS resource utilisation. It was the aim of this study to explore and describe the differences, if any, between these two sub-groups of participants (primary care versus secondary care). This study was also designed to examine the impact of this condition on the health-related quality of life in a cohort of individuals. A substantial amount of data has been collected from individuals in the sample regarding the nature and severity of symptoms. The statistical analysis provides a valuable insight into the symptoms of IBS sufferers, and which factors are associated with those who consult secondary care.

There is increasing evidence to suggest a decrease in health-related quality of life in patients with moderate to severe IBS.<sup>12</sup> The EQ-5D quality-of-life questionnaire is a valid and practical way of measuring health in terms of the following five dimensions: mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. The EQ-5D is a short scale, and thus is easier to use when conducting a telephone interview and less cumbersome than the widely used short-form 36-item health survey questionnaire. The questionnaire has been validated in primary and secondary care and can be used to compare patients in different treatment settings. The EQ-5D also uses generalised questions that are not specific to any particular disease and as such allows comparison with other conditions and the general population.

A commonly held opinion is that population-based individuals have less physical and psychological morbidity than those who consult secondary care. Our study, however, observed little difference in symptomology between individuals managed in primary care versus those managed in secondary care. Contrary to previous estimations that only one in five IBS sufferers are referred to secondary specialist care centres,<sup>15</sup> we established that two-thirds of our population-based sample had been reviewed in secondary care at some stage in their management. This illustrates that the major burden of care for IBS patients is still in primary care, despite the large number of patients seen in secondary care.

In conclusion, there are clinically significant levels of physical and psychological morbidity present in IBS sufferers who are managed solely in primary care. We observed that patients managed entirely in primary care do not have less 'severe' IBS, and this group is just as physically and psychologically disabled as those consulting hospital specialists. Thus, the overall impact of IBS on society may be much greater than currently estimated. Further study to evaluate the effects of patients' symptoms and health-related quality of life over time is also merited.

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## Conflict of Interest

This study was funded in part by a grant from GlaxoWellcome (now GlaxoSmithKline). ID Penman has acted as a paid medical advisor for GlaxoWellcome in the past. GD Smith has also acted as an advisor for GlaxoWellcome in the past.