Inflammatory bowel disease: Greek patients’ perspective on quality of life, information on the disease, work productivity and family support

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Abstract

**Background** The aim of this study was to identify inflammatory bowel disease (IBD) patients’ perspectives regarding everyday life issues.

**Methods** From October 2010 till April 2011, 1,181 IBD patients completed an anonymous questionnaire through the internet (827 cases) or at the outpatient clinic of the participating centers (354 cases), aiming to identify: a) the impact of disease on social life, emotional status and work productivity; b) the source of disease information; and c) the level of support from family members and friends.

**Results** Fifty-five percent of the patients reported that IBD interferes with their social life, while 65% felt stressed, 60% depressed and 19% tired because of it. Disease information (physician/internet) was reported only by 31%, while 26% admitted not discussing their therapy with their gastroenterologist. Forty percent felt that the health service they receive is not satisfactory, with 76% desiring more gastroenterologists, 67% more outpatient clinics, 49% more dieticians and 42% more psychologists specialized in IBD. IBD interfered with working capacity in 40% of the participants, while 57% needed time off of work (ranging from 1-20 days per year). One of three patients (32%) has not informed his work environment about the disease; however, 88% had the support of their family and friends for coping with it.

**Conclusions** Greek IBD patients claim that health-related social life, emotional status and work productivity are severely affected by their disease, whereas they complain about lack of information regarding the therapy. These unmet demands call for immediate action by healthcare providers and society.

**Keywords** Inflammatory bowel disease, quality of life, work productivity, patients’ information on IBD, family support to cope with IBD


**Introduction**

Crohn's disease (CD) and ulcerative colitis (UC), collectively known as inflammatory bowel disease (IBD) are chronic conditions characterized by a relapsing-remitting or chronic active disease. Patients with IBD most often deal with unpredictable, unpleasant and potentially embarrassing gastrointestinal symptoms, in addition to treatment-related side effects.

Although medical therapy aims at controlling intestinal inflammation, minimizing symptoms and preventing complications of the disease, awareness has been raised regarding IBD and its treatment impact on patients’ quality of life, as well as their capacity to carry on with a normal social and professional
patients with IBD visiting the outpatient clinics of the participating centers were invited to participate in a survey organized by the “Hellenic Foundation of Gastroenterology & Nutrition” in collaboration with the “Ulcerative Colitis & Crohn’s Disease Patients’ Association”. The only eligibility criterion was the age range of 18 to 65 years old. Participants were excluded if they had additional co-morbidities impacting adversely their everyday life (i.e. heart, lung or renal failure) and/or if for any reason they were unable to complete the questionnaire. Extra-intestinal manifestations were not an exclusion criterion.

All participants were asked to complete an anonymous questionnaire, aiming to assess the impact of IBD on certain parameters of their everyday life. Return of a completed questionnaire was taken as consent of the patient to participate in the study.

Methods

From October 2010 till April 2011, consecutive, unselected patients with IBD visiting the outpatient clinics of the participating centers were invited to participate in a survey organized by the “Hellenic Foundation of Gastroenterology & Nutrition” in collaboration with the “Ulcerative Colitis & Crohn’s Disease Patients’ Association”. The only eligibility criterion was the age range of 18 to 65 years old. Participants were excluded if they had additional co-morbidities impacting adversely their everyday life (i.e. heart, lung or renal failure) and/or if for any reason they were unable to complete the questionnaire. Extra-intestinal manifestations were not an exclusion criterion.

All participants were asked to complete an anonymous questionnaire, aiming to assess the impact of IBD on certain parameters of their everyday life. Return of a completed questionnaire was taken as consent of the patient to participate in the study.
The questionnaire was formulated by the researchers and was composed of 4 sections (see appendix). Part A collected data regarding patients’ social life and their disease-related emotional status. Part B explored patients’ knowledge regarding IBD and how they obtained information regarding their disease (latest developments and available treatments). Part C dealt with living at their working environment, relationship with their colleagues and supervisor and work productivity. Finally, part D explored patients’ perceptions with regard to the support they receive from their family and friends. The questionnaire was written in Greek and every effort was made to construct questions based on the Greek way of life. The questionnaire was not previously tested on a pilot study and therefore it has not been validated.

This study was approved by the Institutional Review Board at each participating center.

Statistical analysis

All analyses were conducted using the SPSS 17.0 software (Chicago, IL). Descriptive statistics were used to evaluate the response. The Chi-squared test and the Fisher’s exact test were used when testing the hypothesis regarding categorical variables. In all comparisons a P value <0.05 was regarded as significant.

Results

Overall, 1,264 patients were invited to participate in this survey. Forty-two patients declined participation, citing lack of interest and lack of time, 14 patients were excluded because of co-morbidities, whereas 27 patients did not return the questionnaire. Thus, 1,181 IBD patients were subjected to the final analysis. Of those, 827 completed the questionnaire via internet and 354 at the outpatient clinic of the participating centers. Patients’ and disease characteristics, together with their employment status and level of education are provided in Table 1.

Seventeen percent of the patients reported suffering from other non-socially interfering chronic illnesses, 51% had been smoking before the diagnosis while 33% were still smoking. Of note, 69% reported some kind of abdominal pain during the last 2 weeks, while 77% reported excessive flatulence during the same time period. Thirty-two percent of the patients visited a gastroenterologist as soon as their symptoms appeared and 37% did so within a period of 6 months. At the time of completing the questionnaire, 81% of the patients were in remission and 19% had a flare of their disease.

Social life and emotional status

The majority of patients (55%) reported that they had to cancel their participation at a social event because of their disease during the last 2 weeks (Fig. 1). Nine percent of the patients (CD: 11%, UC: 7%) reported that this was a frequent incident (often/all the time). Nineteen percent felt tired either frequently or constantly (CD: 21%, UC: 16%). Sixty percent felt depressed or disappointed because of the disease; this problem was more prevalent in patients with a recent diagnosis of IBD (<5 years). Sixty-five percent reported being stressed because of the disease. Finally, 25% felt anger due to the problems they face and this feeling was more intense in younger and in female patients.

Figure 1 Frequency of cancellation of participation in a social event due to inflammatory bowel disease during the last 2 weeks
Information about the disease

It is of interest that only 31% of our patients reported that they were informed on the latest advances in IBD (from their physician: 30%, through the internet: 16%). Moreover, 26% said that they did not discuss with their gastroenterologist their therapy and did not take part in the decision-making process regarding the treatment options. Almost half of the patients were not happy with the degree of knowledge they have about their disease and the information they received from their doctor. Patients said that they needed more thorough information regarding complications of disease (especially cancer) and treatment-related adverse events (Fig. 2). This was particularly true for patients between the age of 30-39 and for those suffering from CD. Finally, 40% of our patients felt that the health service they receive is not satisfactory, with 76% desiring more gastroenterologists specialized in IBD, 67% more IBD outpatient clinics, 49% more IBD dieticians and 42% more psychologists specialized in IBD (Fig. 3).

Effect on work productivity

A considerable percentage of IBD patients reported that
the disease did not let them select or enter the university they desired (22%) and precluded them from following the career they would have pursued otherwise (28%). Problems associated with the symptoms of IBD were found to interfere with working capability in 40% of the study patients. The problem was more prevalent in patients between the age groups of 18-29 and 40-49 years old. More than half of the patients (57%) needed to take time off of work, because of problems related to the disease or because of the need to visit the outpatient clinic. The days off of work ranged from 1-20 days per year (Fig. 4). One of three patients (32%) had not informed their boss or colleagues about the disease, either because they felt this was a personal matter (65%) or because of fear of possible negative consequences. From those who had informed their working environment, 30% reported that they did not have the desired support. Finally, only 37% of patients reported that the attending physician was willing to be informed on their ability to work and to offer appropriate support.

Support from family and friends

The vast majority of our patients (88%) reported having overwhelming support from their family and friends, without which they would not be able to cope with the burden of their disease. This was tremendously important for patients younger than 29 years old. However, the desire for support from dieticians and psychologists was expressed by 77% and 71% of our patients respectively.

Discussion

Taking into account the abundance of literature data regarding advances in the pathogenesis, diagnosis and therapy of IBD, it is of interest that only a few studies have so far reported on the impact of the disease on patients’ quality of life. Quality of life assessments have been an integral part of almost all recent large randomized controlled therapeutic trials in the field of IBD [4,5], but they offer a transient estimate of how different therapeutic regimens impact on patients’ lives. On the other hand, studies focusing on quality of life in IBD are difficult to compare due to significant methodological differences. However, a common outcome of these studies is that IBD exerts a huge impact on the psychosocial aspects of a patient’s life [6-9]. In a recent study, 63% of patients reported symptoms of anxiety and depression at some point [10]. Other studies have also demonstrated that rates of depression in IBD patients were three times higher than those in the general population [11]. In accordance with these observations, our results show that a substantial number of patients feel depressed (60%) or even angry (25%) because of their disease, which interferes with social life in more than half of the cases. In addition, 19% feel tired either often or constantly, confirming previous reports that IBD patients experience a high rate of fatigue, usually associated with disease activity, poor sleep quality and perceived stress [12].

Surprisingly, only 31% of our patients report being regularly informed about disease advances and only 30% obtained this information directly from the treating physician. Sixteen percent resort to the internet to get information, although the reliability of the medically-oriented websites visited could not be tested since this was not included in the questionnaire. Even more disappointing is the fact that 26% admit that they do not discuss their therapy with the attending gastroenterologist, whereas 40% feel that the health services they receive are not satisfactory. The major reasons for this condition are the lack of appropriately organized outpatients’ clinics, empowered by specialized personnel (qualified IBD physicians and surgeons, IBD nurses, psychologists, stoma-

Figure 4 Days off of work because of inflammatory bowel disease during the last year for those employed
therapists, dietitians, etc.), limited resources and inappropriate structure and function of outpatient clinics in tertiary hospitals in our country. Therefore, it is not surprising that the patients have emphasized the need for more gastroenterologists, outpatient clinics, dieticians and psychologists specialized in IBD.

IBD has a considerable effect on employment behavior of affected persons in their prime working years [13,14]. According to our results, problems associated with the symptoms of IBD interfere with working capability in 40% of patients participating in the study, while more than half need to take time off of work, which ranges from 1 to 20 days per year. This data is in agreement with findings of Boonen et al [15] who reported that IBD has a significant impact on labor force participation, which is higher for CD than for UC and higher in younger and more highly educated patients. IBD-related sick leave rates in their study were 29.1% and 41.1% for UC and CD patients, respectively. The average unemployment rate in a Norwegian cohort was approximately twice higher than in the background population (11.7% versus 4.1%), while IBD-related sick leave rates were 19% and 25% for UC and CD patients, respectively [16]. The higher rate of nonparticipation in the work force, as well as the increased number of days off of work for those who are actually employed, are both major contributors to the indirect costs of illness in IBD patients [17]. In a Swedish study, indirect costs comprised 68% of the total cost (direct plus indirect costs) of IBD to society [18]. The investigators also found that 47% of the indirect costs were related to sickness leave and the remaining 53% were the result of early retirement.

Thirty-two percent of the patients in this study under-report their clinical status to their employers and/or colleagues at work. On the other hand, approximately one third of those who have informed their employers of their disease, claim that they never had the desired level of support. Our results on this parameter are in contrast to the limited data available from previously published studies claiming that IBD patients are not facing significant discrimination at work and most patients seem to disclose IBD to their employers [19-22]. Wyke et al conducted a 6-year prospective study, in which a total of 81% of patients disclosed IBD diagnosis to their employers and 77% stated that their employers had been helpful [23]. These differences may reflect different cultural habits in the working environment between nations and/or different level of fear for job loss in the countries where the studies have been performed.

Finally, our patients quote an overwhelming support from family members and friends, which mirror the strong bonds amongst relatives and close social partners in the Greek society. There is mounting evidence suggesting that a strong social support network in persons with chronic illnesses can facilitate effective coping with stressors, exerts a positive effect on health status and improves the outcome of disease [24,25]. In addition, strong and steady support from family and friends may at least in theory compensate for gaps and pitfalls of a health system that cannot provide the desired support to its patients.

There are several lessons that should be learned from the results of this study. Previous reports have also revealed that physicians frequently underestimate the functional impairment noted in IBD patients [2,3]. In a study by Drossman et al, physicians’ rating about CD severity was poorly correlated with patients’ overall health, since the quality of life scoring was lower in the sociopsychological domain than in the physical domain [26]. The psychological functioning is obviously more difficult to be handled by the physician and therefore it is usually omitted from patient assessment. However, given the importance of functional impairment experienced by our patients, it is obvious that there is an increasing need for gastroenterologists to conceptualize patient health more broadly and incorporate assessments of patient emotional and social well being into treatment decision making.

Our study has several strengths, since the results reported are representative of a large cohort of IBD population in Greece. The study sample is among the largest in the IBD literature, since we had an unusually high response rate to the questionnaire (94.48%), depicting of course the influence which the issues studied had on our patients. It is also of note that 25% of the participants were diagnosed more than 10 years ago, suggesting that responses were provided by patients with a good understanding of their condition. Furthermore, the fact that our study is among the few in the literature to be conducted in southern Europe allowed us to report results that, in some instances, deviate from those already published. Of course our study has several weaknesses as well, since we did not use any validated health related quality of life index to quantify our results; however, our study was not designed to measure exactly this, but rather aimed to give a wider view on IBD patients’ perspectives. Our goal was to use a questionnaire that would be closer to the patients’ “real life” scenario, instead of using a pre-formulated questionnaire designed abroad for patients with different needs and different views to ours. Although it could be argued that, because of this, direct comparison with the results of other studies is difficult, we believe that several conclusions regarding differences in patients’ responses have been noted and are mentioned previously.

In conclusion, the results of this study clearly reinforce the significant impact of IBD on the psychosocial aspects of patients’ lives. Greek IBD patients seek a better organized medical and hospital environment (increased number of IBD outpatient clinics, gastroenterologists, dieticians and psychologists), a tighter relationship with their physician leading to a deeper understanding of their emotional and social status and also the opportunity to receive more disease-related information and a broad educational program for those responsible for human resources in their working environment. IBD patients’ associations and groups in collaboration with IBD specialized medical personnel should stimulate public and/or social authorities to pay more attention and draw action on the above-mentioned unmet needs.
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Summary Box

What is already known:

- Patients with inflammatory bowel disease (IBD) most often deal with unpredictable, unpleasant and potentially embarrassing gastrointestinal symptoms, in addition to treatment-related side effects
- IBD exerts a huge impact on the psychosocial aspects of patients’ lives
- IBD has considerable effect on employment behavior by affecting persons in their prime working years

What the new findings are:

- A substantial number of Greek patients feel depressed (60%) or even angry (25%) because of their disease, which interferes with social life in more than half of the cases
- Only 31% of our patients report regular information for disease advances and only 30% obtained this information directly from the treating physician
- Problems associated with the symptoms of IBD interfere with working capability in 40% of patients, while more than half need to take time off work which ranges from 1 to 20 days per year
- Greek patients quote an overwhelming support from family members and friends, which mirror the strong bonds amongst relatives and close social partners in the Greek society

References


Appendix

Please write your city of residence

PART 1
GENERAL INFORMATION

1. Gender
   - Man [ ]
   - Woman [ ]

2. How old are you?
   1. Under 18 years [ ]
   2. 40-49 years [ ]
   3. 18-29 years [ ]
   4. 30-39 years [ ]
   5. Over 60 years [ ]

3. What kind of inflammatory bowel disease you suffer from?
   - Crohn’s disease [ ]
   - Ulcerative Colitis [ ]

4. How many years ago you were diagnosed with the disease?
   1. Less than 1 year [ ]
   2. 1-5 years [ ]
   3. 6-10 years [ ]
   4. More than 20 years [ ]

5. Apart from idiopathic inflammatory bowel disease, do you suffer from another chronic disease such as psoriatic arthritis, ankylosing spondylitis or psoriasis?
   - Yes [ ]
   - No [ ]
   - Other chronic disease [ ]
   7. (Please specify): [ ]

6. Are you a smoker?
   - Yes [ ]
   - No [ ]

7. Were you a smoker before you were diagnosed with Crohn’s disease / Ulcerative colitis?
   - Yes [ ]
   - No [ ]
   If yes, how many cigarettes did you smoke a day?
   1. Less than 10 [ ]
   2. 10-20 [ ]
   3. More than 20 [ ]

8. What is your employment status?
   PLEASE CHOOSE ONE ANSWER
   1. Employee in full employment [ ]
   2. Employee in partial employment [ ]
   3. Employee unpaid [ ]
   4. Self-employed [ ]
   5. Retired [ ]
   6. Student [ ]
   7. Household [ ]
   8. Unemployed [ ]
   9. No answer [ ]

9. What is the highest level of education you completed?
   PLEASE CHOOSE ONE ANSWER
   1. Primary education [ ]
   2. Secondary education [ ]
   3. University studies [ ]
   4. Postgraduate Studies [ ]

PART 2
IBD & Quality of life

The following questionnaire is designed to determine how you feel during the last 2 weeks.
You will be asked about symptoms you have, as a result of inflammatory bowel disease, how you feel generally and how was your mood.

During the last 2 weeks:

10. How often did you feel tired or exhausted?
    PLEASE CHOOSE ONE ANSWER
    1. Constantly [ ]
    2. Most of the time [ ]
    3. Enough time [ ]
    4. Some time [ ]
    5. Little time [ ]
    6. Hardly ever [ ]
    7. Never [ ]

11. How often you were forced to delay or cancel a social activity because of your bowel problem?
    PLEASE CHOOSE ONE ANSWER
    1. Constantly [ ]
    2. Most of the time [ ]
    3. Enough time [ ]
    4. Some time [ ]
    5. Little time [ ]
    6. Hardly ever [ ]
    7. Never [ ]

12. How much difficulty did you encounter to participate in recreational or sporting activities as a result of your bowel problems?
    PLEASE CHOOSE ONE ANSWER
    1. Great difficulty, it was impossible to take part in activities [ ]
    2. Great difficulty [ ]
    3. Enough difficulty [ ]
    4. Some difficulty [ ]
    5. Little difficulty [ ]
    6. Almost no difficulty [ ]
    7. No difficulty, my bowel problems do not limit my sports or recreational activities [ ]

13. How often you were troubled by pain in the abdomen?
    PLEASE CHOOSE ONE ANSWER
    1. Constantly [ ]
    2. Most of the time [ ]
    3. Enough time [ ]
    4. Some time [ ]
    5. Little time [ ]
    6. Hardly ever [ ]
    7. Never [ ]

14. How often did you feel sorrow or disappointment?
    PLEASE CHOOSE ONE ANSWER
    1. Constantly [ ]
    2. Most of the time [ ]
    3. Enough time [ ]
    4. Some time [ ]
    5. Little time [ ]
    6. Hardly ever [ ]
    7. Never [ ]

15. Overall, how big was the problem encountered with large amounts of gas?
    PLEASE CHOOSE ONE ANSWER
    1. A major problem [ ]
    2. Big problem [ ]
    3. Quite a problem [ ]
    4. Some problem [ ]
    5. Small problem [ ]
    6. Almost no problem [ ]
    7. No problem [ ]

16. Overall, how big was the problem encountered to maintain or achieve the desired weight?
    PLEASE CHOOSE ONE ANSWER
    1. A major problem [ ]
    2. Big problem [ ]
    3. Quite a problem [ ]
    4. Some problem [ ]
    5. Small problem [ ]
    6. Almost no problem [ ]
    7. No problem [ ]
17. How often did you feel relaxed / or without tension?
   PLEASE CHOOSE ONE ANSWER
   1. Never  
   2. Little time  
   3. Some time  
   4. Enough time  
   5. Most of the time  
   6. Almost continuously  
   7. Continuously

18. For how long during the last 2 weeks were you concerned by the feeling that you should go to the toilet despite the fact that your bowel was empty?
   PLEASE CHOOSE ONE ANSWER
   1. Constantly  
   2. Most of the time  
   3. Enough time  
   4. Some time  
   5. Little time  
   6. Hardly ever  
   7. Never

19. How long did you feel angry as a result of problem in your gut?
   PLEASE CHOOSE ONE ANSWER
   1. Constantly  
   2. Most of the time  
   3. Enough time  
   4. Some time  
   5. Little time  
   6. Hardly ever  
   7. Never

PART 3°

IBD & UPDATE

20. Since you felt the first symptoms of Crohn’s disease or Ulcerative colitis, how long after that did you visit a gastroenterologist?
   PLEASE CHOOSE ONE ANSWER
   1. Directly  
   2. 0-6 months  
   3. 6-12 months  
   4. 1-2 years  
   5. 3-5 years  
   6. 5-10 years  
   7. More than 10 years  

21. Are you informed on issues related to the disease and available treatments?
   More than one answer accepted
   1. Yes, I am informed from:
      2. Internet  
      3. Physician  
      4. Printed educational materials (by medical associations, Patients Associations)  
      5. Exchange of views with other patients / patient association  
      6. Other (please specify)  
      7. No, I am not informed

22. Do you discuss with your gastroenterologist, your various treatment options you could get before you are given a particular treatment? Yes ☐ No ☐

23. How satisfied are you with the level of information you have generally about the disease and its impact on your life?
   PLEASE CHOOSE ONE ANSWER
   1. Very  
   2. Enough  
   3. Moderate  
   4. Little  
   5. Not at all

24. On what issues do you consider that you would like more information?
   MORE THAN ONE ANSWERS ACCEPTED
   1. Possible complications of the disease  
   2. Colon cancer as a possible complication  
   3. Nutrition  
   4. Causes of disease  
   5. Drugs & Side Effects  
   6. Surgery  
   7. Create family  
   8. Career  
   9. Other (please specify):

25. Overall, how satisfied are you with the level of health care provided to you?
   Please select an answer
   1. Very  
   2. Enough  
   3. Moderate  
   4. Little  
   5. Not at all

26. Which of the following do you think would improve even further the level of care provided to you?
   Please note the 3 most important
   1. Establishing more outpatient offices in hospitals for Idiopathic Inflammatory Bowel Diseases (IBD)  
   2. More specialized gastroenterologists in IBD  
   3. More specialized surgeons in IBD  
   4. Specialized nurses in IBD  
   5. Psychologists specialized in IBD  
   6. Dieticians specialized in IBD  
   7. Other (please specify):

PART 4°

IBD & Working

Please note the extent to which you agree with the following comments:

27. The Crohn’s disease / ulcerative colitis have disturbed me to choose to study what I’d like to follow under normal conditions
   PLEASE CHOOSE ONE ANSWER
   1. I totally agree  
   2. I probably agree  
   3. I probably disagree  
   4. I strongly disagree  

28. Crohn’s disease / ulcerative colitis have disturbed me to choose a career. I’d like to follow under normal conditions
   PLEASE CHOOSE ONE ANSWER
   1. I totally agree  
   2. I probably agree  
   3. I probably disagree  
   4. I strongly disagree  

29. Crohn’s disease / ulcerative colitis have prevented/prevent me to fulfill my major professional obligations
   PLEASE CHOOSE ONE ANSWER
   1. I totally agree  
   2. I probably agree  
   3. I probably disagree  
   4. I strongly disagree  

30. The last year, how many days did you get time off of work due to your disease?
   PLEASE CHOOSE ONE ANSWER
   1. No  
   2. 1-5 days  
   3. 6-10 days  
   4. More than 10 days  
   5. Other (please specify):
31. Have you told your employer or your colleagues of your condition? 
PLEASE CHOOSE ONE ANSWER
1. I informed my employer only □ (Fill Q. 33 & 34)
2. I informed both my employer and my colleagues □ (Fill Q. 33 & 34)
3. I informed only my colleagues □ (Fill Q. 33 & 34)
4. I have not informed anyone □ (Go to Q. 32)

32. Which is the reason that you did not inform the employer and / or colleagues:
1. More than one answer accepted
2. Because I do not want to be treated differently □ (Go to Q. 35)
3. Because I believe that is my personal issue □ (Go to Q. 35)
4. Other (please specify): ..............................................................

33. Did you have support from the employer and / or your colleagues? 
PLEASE CHOOSE ONE ANSWER
1. Constantly □
2. Several times □
3. A few times □
4. Not at all □

34. Does your employer provide you with appropriate facilities?
Yes □ No □

35. What is the attitude of your doctor in relation to your job? 
PLEASE CHOOSE ONE ANSWER
1. My doctor did not ask if the work is important for me □
2. The doctor gives me sick leave immediately without asking whether I wanted to get it □
3. My doctor asks me about my work and advocates to continue to work or to return to work as soon as possible if this is my choice □
4. None of the above □

PART 5th
IBD & SUPPORT

36. Which of the following parameters do you think would help you to face the difficulties of your disease? 
Please note the 3 most important
1. Support by psychologist □