

**SECTION B**  
**EPIDEMIOLOGY**

# **COELIAC DISEASE IN MALTA**

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## **Introduction**

"Coeliac Disease (CD) is a condition in which the lining of the small intestine is damaged by exposure to wheat, barley, rye and possibly, oats. This damage is caused by gluten, the protein which gives dough its elastic consistency". (Purvis, 1988). CD can present at any age. Proper diagnosis of CD is very important, since there is a wide variety of symptoms, which can be similar to those of other malabsorption states. A definite diagnosis can only be made by the presence of a flat jejunal mucosa on a small intestinal biopsy and the unequivocal clinical response to a GFD. The condition is permanent and is treated by a strict Gluten-free Diet (GFD), which is lifelong. Compliance to the GFD is of utmost importance in order to prevent complications such as infertility, bone disorders and malignancy. The pathogenesis of CD is not fully understood, but the main implicated factors are Gluten, Host factors and possibly, Adenovirus (Dawson, 1987). The incidence of CD in Malta is about 1:4000. Information on this disease in Malta is very limited, and patient education is limited to one visit to a dietitian after diagnosis. Studies were carried out to establish the clinical aspects of the disease, assess patient compliance and establish patient's needs and knowledge. A booklet was set up, printed and distributed to help CD patients understand their condition, and plans for setting up a CD clinic were made.

## **Methodology**

### **Study 1**

#### **Clinical Experience with CD**

The medical records of 70 patients taking gluten-free (GF) supplies from Government Pharmacies were reviewed. 10 of these patients had no evidence of being coeliacs in their medical records. Data obtained included age of onset, symptoms, diagnostic procedures and frequency and nature of follow-ups. The weight and height of the patients was also recorded, since coeliacs are known to have a lower B.M.I. than general population (Bode<sup>1</sup> et al., 1991).

## **Study 2**

### **Dietary Compliance**

21 coeliac patients were interviewed in the Medical Out-patients Department at St Luke's Hospital, regarding knowledge of CD and their diet. These patients also compiled a dietary history. 18 of these patients then underwent a blood test for Anti-gliadin antibodies (AGA). The presence of these antibodies in the patient's serum indicates a dietary indiscrepancy. The results of the blood test were then compared to the dietary history and results of interview. The patients were followed up for an explanation of the results; advice was then given accordingly.

## **Study 3**

### **Patient characteristics, needs and knowledge**

A survey was carried out among 51 CD patients. These patients were required to fill in a questionnaire regarding diagnosis of CD, associated conditions, their knowledge of CD and its treatment, dietary compliance, follow-ups and their attitudes towards pharmacists and the possibility of a CD clinic.

## **Results and Discussion**

### **Study 1**

Out of the 60 cases studied, 19 were <14 years old. The females:male ratio was 1.3:1. 45% (n=27) of patients were diagnosed before 5 years; 21.6% (n=13) between 36 and 45 years. The time from onset of symptoms to diagnosis was >1 year before 1980, and on average, 6 months after 1981, although there were cases after 1981 that took >1 year to be diagnosed. The number of patients diagnosed increased by more than threefold from the '70s to the '80s, which can be attributed to a higher awareness. Other results were: 83% of children had diarrhoea, while only 54% of adults had abdominal symptoms (this is in compliance with Dawson, 1987); proper diagnostic criteria were not followed before 1980; 10% (n=6) of cases had a family history of CD (in compliance with Ellis, 1986); 21.6% (n=13) did not attend for regular follow-up sessions; during follow-ups, 73% (n=44) of patients stated that they were compliant to the GFD, but this was not proved by adequate blood tests; (compliance was related to

regularity of follow-ups; 27% (n=6) had a B.M.I. less than 20, while only 1 patient (5%) had a B.M.I. above 25. (>60% of the Maltese population have a BMI above 25). This could be explained by the fact that the patients, by following a strict diet are less inclined to be overweight or else, they could still be malnourished, especially if their GFD is not enough enough (Bode' et al., 1991).

## Study 2

84% of patients (n=21) attended for the appointment. Results show that AGA levels correlate well with dietary assessments. 67% (n=14) had a negative result, i.e. were compliant. Those with a +ve result also had a history of gluten intake. 9 patients had a total AGA assay, while the other 9 had separate assays for IgA and IgG. IgA is a more specific indicator of dietary compliance, while IgG level is high at diagnosis and declines over a period of up to 1 year after GFD is commenced (Volta et al., 1990). In fact, in this category, non-compliant patients had a +ve IgA and only those who had started GFD since less than a year had a +ve IgG. The results of the interview raise the need for patient education - only 23.8% (n=5) answered correctly to all questions. On average, compliant patients had a better knowledge of CD and GFD.

## Study 3

69% (n=51) of questionnaires were received with a female to male ratio of 1.68:1. Answers show that: 78% (n=40) of patients (or parents) had manual or clerical employment; 10% (n=5) had a family history of CD; 57% (n=29) were diagnosed before 5 years and 17% (n=9) after they were 35 years old; diagnosis was based on biopsy in 78% (n=40), however for 11 patients (22%) it was based on symptoms only i.e. these were not diagnosed according to ESPGAN criteria; only 35% (n=18) had a gluten challenge - this could be due to the revised diagnostic criteria where gluten challenge is not compulsory for all patients (Heymans et al., 1991); 12% (n=6) suffered from associated conditions, including Dermatitis Herpetiformis; 90% (n=46) said that the public should be more aware of CD and only 43% (n=22) said that coeliacs were being well informed (although only through their association) - in fact, 71% (n=36) did not know that some drugs contain gluten; 76% (n=39) attend for regular follow-up sessions - the majority (56%, n=22) of these go on a 6 monthly basis; 84% (n=43) feel the need for a CD clinic, from which they expect staff specialising in CD, information and help; 24% (n=12) admitted to non-compliance; 35% (n=18) said that pharmacists either have no time

or do not have enough knowledge to help them - some added that there were times when not even doctors could answer all their queries. This expresses the need for more awareness among professionals.

## Conclusions

The above results reveal patient education, which is related to dietary compliance, is seriously lacking in CD. A CD clinic, with the active participation of both doctors and pharmacists, would be ideal to improve this situation - patients could even collect their monthly GF supplies from this clinic, where a pharmacist would know more about CD and spare time to help them manage their condition. Compliance could also be assessed in this clinic, using separate AGA assays, which are more specific than a total AGA assay. These measures would be highly effective to avoid long-term complications.

## References

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