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Impact of Coeliac Disease on the Partner's diet- No Altruism

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Background: Coeliac disease is an autoimmune disorder characterised by intolerance to gluten in genetically susceptible individuals. Withdrawal of dietary gluten remains the only effective treatment at present.

Aim: To investigate whether partners of patients with coeliac disease adopt a gluten-free diet to support the patients and to assess the impact of gender on dietary concordance.

Methods: A pilot case-control study was carried out at university teaching hospitals in Auckland, New Zealand and Cardiff, United Kingdom. 38-item dietary questionnaires were completed by patients, controls and their partners. The discordance between the diet of patients or controls and their partners was compared and Student's t -test applied to the results.

Results: The discordance scores were significantly greater in case couples than in control couples. (16.6-female patient couples, 15.1-male patient couples versus 6.2-control couples; $p < 0.00003$). Amongst case couples, the discordance scores were similar irrespective of the gender of the patient. Couples in New Zealand and Wales behaved in a similar manner.

Conclusion: There is no evidence that partners of patients with coeliac disease adopt the gluten free diet of the patient in order to support them with their diet.

Keywords: Coeliac disease; Diet; Gluten-free; Partner; Case-control

Introduction

Coeliac disease is a T-cell driven chronic inflammatory condition, with a prevalence of 1% in European populations [1]. The clinical spectrum of the disease was first described by Dr. Samuel Gee in 1887 [1-3]. He suggested dietary restriction as part of the main treatment for this condition. However, it was not until 1953 that Dr. William Dickie identified correctly a link between the disease and wheat, rye and barley [2] with reversibility of the condition following their exclusion from the diet. Despite scientific advances over the years, the only effective treatment at present is following a gluten-free diet.

Adherence to a strict gluten-free diet is no easy task. Many newly diagnosed coeliac patients suddenly find themselves controlled by food [4] and take time to adjust both mentally and physically to this new dietary restriction. Apart from being restrictive, a gluten-free diet is costly [5,6], complex to follow and leads to a substantial social burden [1]. A recent study highlighted strict adherence rates to a gluten-free diet to range from 42% to 91% [7]. Compliance to the diet is influenced by a host of factors, including sociocultural, emotional and cognitive factors [7-9]. The impact of a gluten-free diet on the patient's quality of life is a widely researched topic [10-12]. However, limited evidence examines the consequences of a gluten-free diet on the patient's partner.

Other conditions requiring dietary changes, such as diabetes, have been shown to influence the diet of patients' wives, but not husbands [13]. It was not clear whether this dietary concordance represents altruism or simply a convenience by women who tend to prepare food in most households. Diabetes specialist nurses often recognise this phenomenon and engage with the partners of male patients when discussing dietary issues.

The aim of the present study was to investigate whether a similar

altruism occurs in the setting of coeliac patients.

Methods

We conducted a case-control study to investigate the dietary concordance amongst coeliac patients and their partners. This pilot study was done as part of a student elective project to test our hypothesis. Data for this study was collected in a 6 week period between September and October 2008. Patients with coeliac disease were identified from a specialist database in New Zealand ($n=95$) and a coeliac clinic in Wales ($n=57$) and invited to participate in the study. These two geographical areas were selected as patients in both centres were easily accessible. As this project was done as part of an elective, we decided to conduct part of the study in New Zealand and part in the United Kingdom, where the prevalence of coeliac disease is similar. Exclusion criteria were subjects who were single/widowed, people on 'special' diets or any couple in which both partners had coeliac disease. Special diets included those on modified diets- for example a liquid diet secondary to PEG feeding.

Patients were sent a postal questionnaire regarding their present diet. In order to simplify the study, and shorten the questionnaire, as

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much as possible, no other details about their coeliac disease were collected. Furthermore, their adherence to the gluten free diet was not assessed. The partner of each patient was asked to complete an identical questionnaire. An age and sex-matched control group was identified from outpatient clinics and hospital staff at each institution as the cases, who received identical questionnaires to be completed by them and their partner.

Each couple received a questionnaire containing a list of thirty-eight gluten-free and gluten containing food items and was based on a questionnaire used in earlier work [14]. Participants were asked to indicate food items they recalled consuming in the last month and were given a period of two weeks in which to complete and return the questionnaires.

The analysis compared the number of food items the couples chose differently. The discordant items were counted to give a discordance score. A low discordance score indicated that couples ate similar foods, whereas a high score reflected dissimilarity in foods consumed by the couple. The scores were compared using unpaired Student's t-test.

Written informed consent was obtained from all participants and ethical approval was granted by the Southmead Research Ethics Committee in the United Kingdom (08/H0102/69) and the Northern X Regional Ethics Committee in New Zealand.

Results

Thirty-five (37%) patients' questionnaires were returned in New Zealand, of which 3 were excluded from the analysis because two patients were single and one patient's partner was undergoing PEG feeding. Of the thirty two replies from eligible couples, in twenty four the patient was female (Table 1). Twenty-six (46%) patients' questionnaires were returned in United Kingdom; all of these patients had partners. Twenty of the patients were female (Table 1).

There was striking agreement between the discordance scores amongst patients irrespective of the gender of the patient or their place of treatment (Table 2). When the patient was from UK, the scores were 18.7 and 18 for male and female patient couples, respectively. For patients from New Zealand, the score were 12.4 and 16.5 for male and female patient couples, respectively. Meanwhile for control couples, the scores were significantly lower in each centre. The scores from the two centres were combined to reduce the impact of the small sample size; the discordance scores were 16.6, 15.1 and 6.2 for female patient couples, male patient couples and control couples respectively. Patient couples had significantly greater discordance scores than control couples; $p<0.00003$ for either set of patient couples versus controls

(Table 2). There were significant differences in the scores obtained from the two centres within each group.

Discussion

The evidence of the impact of coeliac disease on the patient's partner is limited. In this small pilot study, conducted at two clinical centres we found that patients with coeliac disease and their partners had markedly discordant diets. The degree of discordance was not influenced by gender or the setting in which they are treated. In fact, the discordance scores were similar in each of the four patient couple groups. Despite our sample size, this study has shown a significant result that has not previously been reported in the literature.

In diabetes, female partners of male patients have diets that are similar to that of the patient [13]. Possible reasons include convenience, as women more often tend to be responsible for family meals and to have to prepare different foods for different people would be inconvenient; altruism, consciously adopting the male patients' diet as a supportive act; or simply a conscious decision to eat the healthy diet of diabetic patients encouraged to avoid refined sugars and fat. By contrast, male partners of female diabetic patients show less dietary concordance. It could be suggested that males are less aware of healthy eating, less altruistic and less likely to prepare meals, while expecting to eat as they would choose if their partner were not diabetic (i. e. chauvinist).

These data with diabetic patients are strikingly different than the present data with coeliac disease patients. The present study suggests that partners cannot or will not eat the same food as patients with coeliac disease. The reasons behind this observation have not been explored. Potential explanations include the cost of eating a gluten free diet [5,6]; limited palatability [15]; or the higher calorie content of gluten free flour substitute. A further explanation may be that unlike the low fat, low sugar diet of diabetes, a gluten-free diet may not be perceived as 'healthy' [2] and only benefits the coeliac patient.

The consequences of the discordance are that members of the same family eat different foods which may impact on the social aspects of mealtimes; there may be additional stress in kitchens as food preparers try to avoid contamination; there may be extra food waste; and finally, a risk of isolation on the part of patients. This would be an interesting topic for further research.

Anecdotally, when second or third family members are found to have coeliac disease, the proband tends to experience a sense of relief (as well as guilt) that they can help the newly diagnosed relative and share their experiences and food. This suggests that patients would value sharing the gluten-free diet with other people and may feel

	Patients New Zealand (n=32)		Controls New Zealand (n=9)		Patients United Kingdom (n=26)		Controls United Kingdom (n=16)	
	Male	Female	Male	Female	Male	Female	Male	Female
Sex	n=8	n=24	n=3	n=6	n=6	n=20	n=6	n=10
Age	57.3 (38-79)	44.4 (20-73)	57 (40-83)	44.8 (23-63)	51.8 (31-65)	61.9 (40-75)	58.3 (40-73)	44.9 (22-86)

Table 1: Demographic details of participants.

Source	Male patient couple	Female patient couple	Control couple	P Male patient couple vs control	P Female patient couple vs control
UK	18.7	18	6.9	<0.00003	<0.0000003
NZ	16.5	12.4	4.8	0.009	0.00001
Combined	15.1	16.6	6.2	<0.00003	<0.000001

*A low discordance score indicates that couples ate similar foods. The scores were compared using unpaired Student's t-test.

Table 2: Mean discordance scores*.

isolated or unsupported when they are the only person who has to eat a gluten-free diet.

Limitations

This study has a number of limitations which are explored below. Firstly, the number of participants in the study was small. In particular, the number of controls at both centres was small and on analysing the final results, a mismatch in age between the female patients and controls in the United Kingdom was seen (Table 1). This study was conducted within a 6 week time period which limited the number of participants we were able to recruit. Secondly, the study utilised a dietary recall questionnaire, rather than a food diary which is vulnerable to recall bias. Coeliac patients, whose health and wellbeing depends on being compliant to a gluten-free diet, are much more likely to be aware of food items consumed than their unaffected partners. Thirdly, we did not explore the differences in cultural, educational and socioeconomic factors between the populations in the two different countries. It was impossible to account for these factors in a postal questionnaire. However, it is important to note that different cultures may find dietary adjustment easier [7], which limits the generalizability of our results.

Fourthly, the study did not assess the compliance of coeliac patients to a gluten-free diet. We can only speculate about the impact of dietary discordance on adherence. Taken at face value, discordance means the patient is adhering to their diet and their partner continues to eat their normal diet. It would be interesting to address the topic of concordance in future work: concordance may mean both parties are eating a gluten-free diet or that neither is! Similarly it would be of interest to address whether discordance changes with time and whether newly diagnosed patients have more support from their partner. A recent study [16] has suggested a reliable and simple gluten-free diet score to assess compliance amongst patients, which could be utilised in future work. Finally, it would be of great interest to compare the reported diet, the discordance score and the impact of disease outcomes. Our survey did not explore the nature of each couple's relationship, for example the duration of the relationship, whether they lived together and which partner was involved in meal preparation. These factors are likely to have an impact on levels of dietary discordance but were beyond the scope of this postal survey.

Despite its limitations, this study has highlighted some interesting and novel observations. In future work we intend to conduct a larger study on this subject incorporating sufficient data to account for the limitations of this project.

Conclusion

This study has demonstrated no evidence to suggest that partners of patients with coeliac disease adopt the gluten-free diet of the patient in order to support them with their diet. This should have consequences for the way medical and dietetic staff interact with patients and their relatives. When we discuss food with patients we must be aware of their potential feeling of isolation and be careful to direct dietary advice to the patient, irrespective of their gender.

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Irasha Hettiarachchi conceived the study, participated in data collection, data analysis and drafted the manuscript.

Chris Probert participated in the design of the study, carried out data analysis and drafted the manuscript.

David Rowbotham participated in the design of the study and data collection.

Gillian Swift participated in the design of the study and data collection.

Rosemary Crimmins helped to collect data for the study and recruited study participants.

Megan Gallagher participated in the design of the study.

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