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Predictors of adherence to a gluten-free diet in coeliac disease: do knowledge, attitudes, experiences, symptoms and quality of life play a role?

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ABSTRACT

Objective: To identify the relationship between adherence to a gluten-free diet (GFD) and demographic characteristics, knowledge, attitudes and beliefs regarding coeliac disease and GFD, experiences of following a GFD, symptoms and QoL.

Research methods & Procedures: Patients with CD were recruited from outpatient clinics. Adherence to GFD was assessed using the 'Coeliac Dietary Adherence Test' (CDAT) and 'GFD-Score' (GFD-S). Knowledge, attitudes, experiences, symptoms and QoL were assessed using existing questionnaires. Multivariate logistic regression was performed.

Results: Overall, 116 patients with CD were included (48±16 years, 70% female). Based upon the CDAT questionnaire, 58 (50%) were adequate adherers, whereas based upon GFD-S, 86 (74%) were adequate adherers. When adherence was measured using CDAT, being female was associated with lower odds of adherence (OR=0.36, p=0.028), and better emotional wellbeing was associated with higher odds of adherence (OR=1.19, p<0.001). When adherence was measured using GFD-S, membership in a support group (OR=6.17, p=0.002), stronger beliefs about the chronicity of CD (OR=1.15, p=0.059) and weaker beliefs on accident/chance causing CD (OR 1.94; p=0.05) were associated with greater odds of adherence. Difficulties when eating with family/friends (OR=0.98, p=0.005) and weaker beliefs on immunity causing of CD (OR 0.77; p=0.031) were associated with lower odds of adherence.

Conclusion: The association between gender, attending support groups, attitudes, experiences, and QoL with adherence to a GFD should be considered by healthcare professionals managing patients with CD.

INTRODUCTION

Coeliac disease is a chronic autoimmune disorder that affects approximately 1% of the general population[1]. It is characterised by inflammation of the small intestinal mucosa and subsequent villous atrophy, triggered by ingestion of the gluten protein. Gluten ingestion leads to several intestinal (e.g. diarrhoea, abdominal pain) and extraintestinal (e.g. osteoporosis) symptoms in patients with coeliac disease[2]. If left untreated, coeliac disease can lead to serious complications including intestinal cancers[3], osteoporosis and infertility[4,5]. The only available treatment is a strict lifelong gluten-free diet (GFD) which should result in complete symptomatic, histological and serological remission, and prevention of these complications[6].

Although a GFD is the only management strategy for coeliac disease, strict adherence varies from 42% to 91%[7]. Due to the importance of following a strict GFD, several studies have investigated the factors that influence dietary adherence in an attempt to support patients with their condition and devise interventions that could potentially improve adherence[7-9]. Systematic reviews have previously indicated the factors associated with adherence include a wide range of variables including socio-demographic characteristics, knowledge, attitudes, experiences, symptoms and quality of life (QoL)[7,9].

Limited education is an attributing factor to inadequate adherence[10], and greater knowledge of the GFD has been associated with better adherence to a GFD in some studies[9,11]. Psychological factors, such as illness representations and treatment beliefs have also been associated with adherence, with a stronger belief about the serious consequences of CD being predictive of improved GFD adherence[12]. Patients' experience following a GFD may also influence their adherence, indeed, patients who are able to follow a GFD when travelling and eating out have been shown to be more adherent to a GFD[9,11,13].

The GFD presents the challenge of altering long-established eating habits and can therefore negatively impact quality of life (QoL) and adherence to the diet[7,14,15]. A large study of patients with coeliac disease found that younger age at diagnosis, newly diagnosed patients, latency of diagnosis and dissatisfaction with information from healthcare professionals reduces QoL[16]. Although few studies have demonstrated associations between specific QoL domains and adherence to a GFD, evidence suggest no association between overall QoL and adherence[7,17-20].

Therefore, many aspects of knowledge, attitudes and beliefs, experiences and symptoms, and QoL have been individually associated with adherence to a GFD in coeliac disease. However, these factors are often investigated in isolation, and yet may themselves be related; however, there is limited research on the associations between all such variables with adherence to a GFD.

The aim of this study was to identify the relationship between adherence to a GFD and demographic characteristics, knowledge, attitudes and beliefs regarding coeliac disease and a GFD, experiences of following a GFD, symptoms and QoL.

METHODS

A cross-sectional questionnaire survey of adherence to a GFD together with knowledge, attitudes, experiences, symptoms, and QoL was undertaken in patients with coeliac disease. Ethical approval for this study was provided by National Research Ethics Service Committee North East – Sunderland (Reference: 13/NE/0096).

Participants

Inclusion criteria were patients aged 18 years or over who had been diagnosed with coeliac disease for at least 6 months (positive diagnosis recorded in medical notes using standard approaches, i.e. duodenal biopsy or IgA tissue transglutaminase). Exclusion criteria were patients with any other self-reported gastrointestinal disorder, dietary restrictions other than a GFD, or eating disorder.

Participation was voluntary and confidential. Patients were provided with written and verbal explanation of the study and those wishing to participate signed a consent form. The questionnaires were completed by patients in the clinic with the gastroenterologist, dietitian and researcher not present in order to limit response bias. The researcher was available to provide guidance on completing the questionnaires if required. All data were anonymised on collection.

Questionnaires

Information on age, gender, marital status, employment status, and ethnicity were collected from self-reports. Patients were also asked regarding the length of time since their diagnosis, membership to a support group for coeliac disease patients, and frequency of visits to a doctor

and dietitian in the previous two years. Adherence to a GFD, knowledge, attitudes, experiences, symptoms, and QoL were assessed via completion of a combined questionnaire.

Adherence

Adherence was measured using two validated questionnaires, the Coeliac Dietary Adherence Test (CDAT) [21] and the Gluten-Free Diet Score (GFD-S)[22].

The CDAT contains seven questions rated on a 5-point Likert scale. Higher CDAT sum score denote poorer GFD adherence this can be used to categorise "adequate adherence" (<13) and "inadequate adherence" (≥13)[21]. CDAT correlates highly with standardised dietitian evaluation of adherence and was found to be superior to tissue transglutaminase serology[21].

The GFD-S contains six questions rated via dichotomous response. The sum score has five levels (0-4) that are grouped into "poor GFD adherence" (score 0-1); "adherence with some error" (score 2); and "strict GFD adherence" (score 3-4). In the current study, these categories were collapsed into: "inadequate adherence" (score 0-2), and "adequate adherence" (score 3-4) to enable comparison between the categorisation of patients using CDAT and GFD-S.

Knowledge

Knowledge of coeliac disease and GFD was measured using a 30-item questionnaire[11]. Patients were required to identify both gluten-containing and gluten-free foods and the potential complications prevented by gluten exclusion. A mark was provided for every correctly answered question, with total score ranging from 0 to 30, with a higher score indicating a better knowledge regarding coeliac disease and GFD.

Attitudes

Attitudes and beliefs about CD and the GFD were assessed using two validated questionnaires, the Beliefs about Medications Questionnaire (BMQ)[23] and the Revised Illness Perception Questionnaire (IPQ-R)[24].

The BMQ consists of 10 questions rated using a 5-point Likert scale (1=strongly disagree, 5=strongly agree). It assesses cognitive representation of medication, but has been validated across many illness groups whereby the term "medication" is substituted for specific terminology related to the disease of interest, in the case of coeliac disease the questions therefore relate to GFD. Ten questions were used to measure specific treatment beliefs; five questions measured *Specific-Necessity* (positive health effects) and five questions measured *Specific-Concerns* (concerns about adverse consequences) about coeliac disease and the GFD.

The mean sum scores for Specific-Necessity and Specific Concerns subscales were calculated. The difference between *Specific-Necessity* and *Specific-Concerns* was also calculated in line with standard psychometrics by subtracting the Specific-Necessity score from the Specific-Concern score, in order to represent a cost-benefit measure[25].

The IPQ-R consists of 84 questions using a 5-point Likert scale (1=strongly disagree, 5=strongly agree) or yes/no answers. It provides a quantitative measurement of components of illness representation, as described by Leventhal's Self-Regulatory model [26,27]. The IPQ-R can be modified so that 'illness' can be substituted for specific terminology related to the condition of interest, in this case coeliac disease. It is divided into the following sections: (i) Identity (of symptoms); (ii) Causes of disease (psychological, risk factors, immunity, accident or chance); and (iii) Seven subscales (consequences, timeline (acute/chronic), personal-control, treatment-control, illness-coherence, timeline cyclical and emotional representations).

All items for each of the subscales for the IPQ-R are summed to provide an overall score, with higher scores represent stronger beliefs held about each subscale, except for the "causes of disease" where low scores represent stronger beliefs. Personal-control, treatment-control and illness-coherence represent positive beliefs, whilst identity, consequences, timeline acute/ chronic, timeline cyclical represent negatively held beliefs.

Experiences

Experiences of following a GFD was measured using a questionnaire developed by the Canadian Coeliac Association Professional Advisory Board and Health Canada, consisting of 52 questions and responses measured using a 5-point Likert scale. The questionnaire measures difficulties encountered in patients following a GFD in six subscales: purchasing gluten-free foods; food preparation; eating with family/friends; eating in restaurants; eating at school/work; and travelling. A score was devised by calculating the percentage answered with "often" or "very often" within each subscale and a total score was devised by calculating the percentage of all questions answered "often" or "very often". Higher scores denote greater difficulties in following a GFD.

Gut symptoms

Symptoms were assessed through the validated Coeliac Specific Index [28], consisting of 16 questions rated via a 5-point Likert scale. Possible sum scores range from 6-80 with higher scores denoting greater symptoms. The Coeliac Specific Index assessed domains of symptoms specific to coeliac disease (11 questions) and general health (5 questions).

Quality of life

The validated Coeliac Disease Questionnaire was used to assess health-related QoL [29]. It contains 28 questions assessed through a 7-point Likert scale. It consists of four domains (seven questions each) assessing: emotional wellbeing; social problems; disease-related worries; and gastrointestinal symptoms. Higher additive scores are associated with better QoL.

Statistical analysis

The sample size required was estimated based upon the number of variables that would be analysed in the largest model for logistic regression, in which a minimum of 5 participants per variable is needed [30]. It was estimated that the largest model in this study would contain 23 variables, and therefore a total of 115 participants were required.

The agreement between the two adherence questionnaires (CDAT, GFD-S) in categorising patients as having adequate and inadequate adherence was measured using Cohen's kappa which was compared with the standards of Landis and Koch[31].

Continuous data were compared between adequate and inadequate adherence using independent samples t-test, and categorical data using chi-squared test. Univariate regression analyses were used to identify associations between demographic characteristics, knowledge, attitudes, experiences, symptoms and QoL, with adherence to a GFD. Subsequently, multivariable logistic regression analysis was performed to identify the association between all these domains (demographic characteristics, knowledge, attitudes, experiences, symptoms, QoL) and adherence to a GFD. The variables entered in the multivariate logistic regression model included (i) total scores of each questionnaire, where available, and (ii) all variables that tended towards significant association with adherence following the univariate regression analysis ($p<0.1$). Separate analyses were performed for the two different methods used to define adherence (CDAT and GFD-S).

P values <0.05 were considered statistically significant. Data were analysed using IBM SPSS statistics for Windows (version 25, Armonk, New York, USA).

RESULTS

Overall, 154 coeliac patients were approached and screened in clinic of whom 123 were eligible to participate. Of the 31 ineligible patients, 12 had been diagnosed with CD for less than 6 months, nine had a self-reported gastrointestinal disorder other than CD, and 10 self-reported

to be following another form of dietary restriction and, thus, were excluded from the survey. The questionnaire was administered to 123 eligible patients of whom 116 successfully completed and returned the questionnaire to the researcher (94% response rate).

The mean age of the population was 48 (range 19-79) years with a mean duration of diagnosis of 8.9 (range 0.5-35) years. Those of white ethnicity formed the largest ethnic group in the sample (76%), and a total of 70% of the population were female. Sixty-two (53%) reported being members to a coeliac patient support group. The mean number of visits to a doctor and dietitian regarding their coeliac disease in the past two years were 2.6 (range 0-12) and 1.0 (range 0-7), respectively. The demographic characteristics are displayed in Table 1.

	Descriptive data (n=116)
Age (years), mean (SD)	48 (16)
Gender, n (%)	
Males	35 (30)
Females	81 (70)
Ethnicity, n (%)	
White	99 (85)
Asian	8 (7)
Black	2 (2)
Arab	4 (3.4)
Mixed	2 (2)
Other	1 (1)
Marital status, n (%)	
Single	36 (31)
Married/civil partnership	70 (60)
Cohabiting	9 (8)
Widowed	1 (1)
Employment, n (%)	
Employed	72 (62)
Unemployed	14 (12)
Retired	30 (26)
Being member of coeliac disease support group, n (%)	62 (53)
Duration of coeliac disease diagnosis (years), mean (SD)	8.8 (10.1)
Number of appointments with gastroenterologist in previous 2 years, mean (SD)	2.6 (2.3)
Number of appointments with dietitian in previous 2 years, mean (SD)	1.0 (1.3)

Table 1: Demographic and clinical characteristics of 116 patients with coeliac disease participating in the survey

When adherence to GFD was measured using the CDAT, adequate adherence was reported in 58 (50%) patients adhering. The mean CDAT score in the whole study population was 13.3 (3.6) and ranged between 7-25. When adherence to GFD was measured using the GFD-S, adequate adherence was reported in 84 (74%) patients. There was agreement between CDAT

and GFD-S in assigning patients to adequate or inadequate adherence on 70/116 (60%) of occasions, indicating only fair agreement (k=0.21, p=0.011) (**Figure 1**).

		Coeliac Dietary Adherence Test (CDAT)		
		Adequate adherence (score <13)	Inadequate adherence (score ≥13)	**Total**
Gluten-Free Diet Score (GFD-S)	Adequate adherence (score 3-4)	49 (42%)	37 (32%)	86 (74%)
	Inadequate adherence (score 0-2)	9 (8%)	21 (18%)	30 (26%)
	Total	**58 (50%)**	**58 (50%)**	**116 (100%)**

Figure 1. Adherence to GFD among 116 patients with coeliac disease comparing categorisation by the Coeliac Dietary Adherence Test (CDAT) and the Gluten-Free Diet Score (GFD-S)

When adherence was measured using CDAT, significantly fewer females were adequate (n=34, 59%) than inadequate adherers (n=47, 81%; p=0.009), with being female being associated with lower odds of adherence to the GFD (OR 0.33, p=0.010). Greater numbers of patients who were members of a support group for coeliac disease were adequate (n=37, 64%) than inadequate adherers (n=25, 43%; p=0.026), with being a member of a support group being associated with greater odds of adherence to the GFD (OR 2.33, p=0.027). Fewer challenges when eating with friends/family were reported in adequate (mean 19.1, SD 21.5) than inadequate adherers (mean 33.5, SD 29.5; p=0.004), with facing greater challenges when eating with friends/family being associated with lower odds of adherence to the GFD (OR 0.98, p=0.005).

Better QoL was reported in adequate (mean 36.7, SD 4.3) that inadequate adherers (mean 31.7, SD 6.6; p<0.001), with a better QoL being associated with greater odds of adherence to the GFD (OR 1.04, p<0.001). Fewer symptoms were reported in adequate (mean 32.0, SD 9.8) than inadequate adherers (mean 39.7, SD 10.9; p<0.001), with experiencing greater symptoms being associated with lower odds of adherence to the GFD (OR 0.93, p<0.001). Five illness-related attitudes (identity, cause accident/chance, personal control, timeline cyclical and emotional representation) were associated with adherence to a GFD (Table 2). Age, ethnicity, employment and knowledge were not associated with adherence to a GFD (Table 2).

| | Adherence to GFD | | | | | | | | | |
| | Coeliac Dietary Adherence Test (CDAT) | | | | | Gluten Free Diet Score (GFD-S) | | | | |
	Adherers (score 0-12) n=58	Inadequate adherers (score ≥13) n=58	P value	OR (95% C.I.) of being an adequate adherer[1]	P value	Adherers (score 3 and 4) n=86	Inadequate adherers (score 0 and 2) n=30	P value	OR (95% C.I.) of being an adequate adherer[1]	P value
Demographic characteristics										
Age, years	50 (17)	45 (15)	0.139	1.02 (0.99 - 1.04)	0.138	48 (16)	46 (18)	0.474	1.01 (0.99 - 1.04)	0.433
Gender, n (%)										
Male	24 (41)	11 (19)	**0.009**	Ref	**-**	25 (29)	10 (33)	0.661	Ref	-
Female	34 (59)	47 (81)		0.33 (0.14 - 0.77)	**0.010**	61 (71)	20 (67)		1.22 (0.50 - 2.97)	0.662
Ethnicity, n (%)										
White	51 (88)	48 (83)	0.405	Ref	-	76 (88)	23 (77)	0.277	Ref	-
Asian	2 (3)	6 (10)		0.31 (0.06-1.63)	0.168	5 (6)	3 (3)		0.50 (0.11-2.27)	0.373
Black	2 (3)	0 (0)		-	-	2 (2)	0 (0)		-	-
Arab	2 (3)	2 (3)		0.94 (0.13-6.95)	0.953	2 (2)	2 (2)		0.30 (0.04-2.27)	0.245
Mixed	1 (2)	1 (2)		0.94 (0.57 – 15.5)	0.966	1 (1)	1 (1)		0.30 (0.18-5.03)	0.405
Other	0 (0)	1 (2)		-	-	0 (0)	1 (1)		-	-
Marital status, n (%)										
Single	17 (29)	19 (33)	0.734	Ref	-	26 (30)	10 (33)	0.266	Ref	-
Married/in a registered same-sex civil partnership	36 (62)	34 (59)		1.18 (0.53-2.65)	0.682	52 (61)	18 (61)		1.11 (0.45-2.75)	0.820
Widowed	5 (9)	4 (7)		-	-	8 (9)	1 (3)		-	-
Cohabiting	0 (0)	1 (2)		-	-	0 (0)	1 (3)		-	-
Employment, n (%)										
Employed	35 (60)	37 (64)	0.646	Ref	-	57 (66)	15 (50)	0.190	Ref	-
Unemployed	6 (10)	8 (14)		0.79 (0.25 – 2.52)	0.684	8 (9)	6 (20)		0.35 (0.11 – 1.17)	0.088
Retired	17 (29)	13 (22)		1.38 (0.59 – 3.26)	0.459	21 (24)	9 (30)		0.61 (0.23 – 1.61)	0.322
Duration of coeliac disease diagnosis, years	10 (12)	8 (7)	0.179	1.03 (0.99 - 1.07)	0.189	8.3 (8.1)	10.3 (14.5)	0.487	0.98 (0.95 - 1.02)	0.368
Being member of coeliac disease support group, n (%)										
No	21 (36)	33 (57)	**0.026**	Ref	**-**	32 (37)	22 (73)	**0.001**	Ref	**-**
Yes	37 (64)	25 (43)		2.33 (1.10 – 4.91)	**0.027**	54 (63)	8 (27)		4.64 (1.85 – 11.64)	**0.001**
Appointments with gastroenterologist in 2 years	2.7 (2.4)	2.5 (2.2)	0.612	1.04 (0.89 – 1.22)	0.608	2.8 (2.4)	2.0 (1.7)	**0.037**	1.22 (0.98 – 1.53)	0.080
Appointments with dietitian in 2 years	0.9 (1.1)	1.1 (1.5)	0.403	0.89 (0.67 – 1.18)	0.402	1.1 (1.4)	0.7 (0.9)	0.063	1.35 (0.91 – 1.99)	0.133
Knowledge										

| | Adherence to GFD | | | | | | | | | |
| | Coeliac Dietary Adherence Test (CDAT) | | | | | Gluten Free Diet Score (GFD-S) | | | | |
	Adherers (score 0-12) n=58	Inadequate adherers (score ≥13) n=58	P value	OR (95% C.I.) of being an adequate adherer[1]	P value	Adherers (score 3 and 4) n=86	Inadequate adherers (score 0 and 2) n=30	P value	OR (95% C.I.) of being an adequate adherer[1]	P value
GFD knowledge questionnaire	17.6 (5.1)	16.6 (5.2)	0.308	1.01 (0.99 - 1.03)	0.306	17.7 (5.3)	15.5 (4.4)	**0.038**	1.03 (1.00 - 1.05)	**0.042**
Attitudes										
Beliefs about Medicines Questionnaire (BMQ)										
Necessity score	2.9 (1.4)	2.7 (0.9)	0.343	1.2 (0.9-1.6)	0.340	2.9 (1.3)	2.5 (0.8)	0.084	1.3 (0.9-1.9)	0.166
Concern score	3.0 (1.0)	2.8 (0.7)	0.328	1.2 (0.8-1.9)	0.325	3.0 (0.9)	2.9 (0.7)	0.319	1.3 (0.8-2.0)	0.378
Necessity-concerns differential	-0.1 (2.1)	-0.2 (1.2)	0.878	1.0 (0.8-1.3)	0.877	-0.1 (1.9)	-0.3 (1.1)	0.512	1.1 (0.8-1.4)	0.608
Illness Perception Questionnaire (IPQ)										
Identity score	2.3 (2.8)	4.2 (3.5)	**0.002**	0.82 (0.72 - 0.94)	**0.003**	3.2 (3.3)	3.6 (3.3)	0.505	0.96 (0.85 - 1.08)	0.501
Cause psychological[2]	20.8 (8.4)	19.3 (7.4)	0.292	1.03 (0.98 - 1.08)	0.293	20.5 (8.0)	18.8 (7.7)	0.322	1.03 (0.97 - 1.09)	0.322
Cause risk factors[2]	26.0 (9.2)	23.7 (8.1)	0.145	1.03 (0.99- 1.08)	0.148	25.7 (9.0)	22.3 (7.3)	**0.040**	1.06 (1.00 - 1.12)	0.065
Cause immunity[2]	9.5 (4.7)	8.0 (4.0)	0.056	1.09 (1.00 – 1.19)	0.060	9.2 (4.6)	7.6 (3.6)	0.056	1.10 (0.98 - 1.23)	0.094
Cause accident/chance[2]	5.6 (3.6)	4.3 (2.2)	**0.022**	1.16 (1.02 – 1.33)	**0.026**	5.4 (3.2)	3.5 (2.0)	**<0.001**	1.38 (1.10 - 1.41)	**0.006**
Timeline acute/chronic	26.8 (3.5)	26.0 (4.1)	0.259	1.06 (0.96 - 1.17)	0.260	27.2 (3.3)	24.3 (4.6)	**<0.001**	1.21 (1.08 - 1.35)	**0.001**
Consequences	19.5 (4.1)	20.5 (4.2)	0.199	0.94 (0.86 – 1.03)	0.198	20.1 (4.3)	19.9 (3.7)	0.840	1.01 (0.91 - 1.12)	0.838
Personal control	24.0 (4.1)	23.0 (3.2)	0.142	1.08 (0.98 - 1.19)	**0.026**	23.8 (3.9)	22.6 (3.0)	0.151	1.09 (0.97 – 1.22)	0.153
Treatment control	18.3 (3.5)	17.4 (2.5)	0.104	1.11 (0.98 - 1.26)	0.106	17.9 (3.2)	17.6 (2.5)	0.671	1.03 (0.90 - 1.18)	0.668
Illness coherence	19.6 (4.5)	18.1 (3.9)	0.052	1.09 (1.00 - 1.20)	0.056	19.4 (4.3)	17.1 (3.8)	**0.009**	1.14 (1.03 - 1.26)	**0.012**
Timeline cyclical	10.3 (3.6)	12.0 (3.4)	**0.008**	0.87 (0.78 – 0.97)	**0.011**	10.7 (3.7)	12.5 (3.2)	**0.019**	0.87 (0.77 – 0.98)	**0.022**
Emotional representation	14.0 (4.4)	17.2 (5.0)	**<0.001**	0.86 (0.79 - 0.94)	**0.001**	15.1 (4.7)	17.0 (5.4)	0.077	0.93 (0.85 – 1.01)	0.080
Experience										
Purchase of GF food	40.1 (27.9)	40.7 (28.6)	0.902	1.00 (1.00 - 1.01)	0.901	39.7 (27.9)	42.5 (29.3)	0.639	1.00 (0.98 - 1.01)	0.635
GF preparation	26.3 (24.8)	34.9 (27.7)	0.080	0.99 (0.97 - 1.00)	0.082	27.3 (24.0)	40.0 (31.2)	**0.049**	0.98 (0.97 – 1.00)	**0.027**
Eating with family/friends	19.1 (21.5)	33.5 (29.5)	**0.004**	0.98 (0.96 - 0.99)	**0.005**	22.4 (24.5)	37.3 (29.9)	**0.008**	0.98 (0.97 - 1.00)	**0.011**
Eating in restaurant	48.3 (29.8)	51.0 (32.1)	0.642	1.00 (1.00 - 1.01)	0.638	50.7 (30.9)	46.7 (30.9)	0.545	1.00 (0.99 - 1.02)	0.542
Eating at school/university/work	21.6 (20.4)	23.7 (24.5)	0.608	1.00 (0.98 - 1.01)	0.605	19.9 (20.3)	30.4 (26.6)	0.055	0.98 (0.96 – 1.00)	**0.031**
Travelling	36.0 (26.7)	45.8 (34.4)	0.090	0.99 (0.98 - 1.00)	0.091	39.0 (31.0)	46.3 (31.0)	0.271	0.99 (0.98 - 1.01)	0.269
Total score	31.8 (20.0)	38.5 (22.9)	0.098	0.99 (0.97 - 1.00)	0.099	33.2 (20.5)	40.6 (24.3)	0.106	0.98 (0.97 - 1.00)	0.108
Symptoms										

	Adherence to GFD									
	Coeliac Dietary Adherence Test (CDAT)					Gluten Free Diet Score (GFD-S)				
	Adherers (score 0-12) n=58	Inadequate adherers (score ≥13) n=58	P value	OR (95% C.I.) of being an adequate adherer[1]	P value	Adherers (score 3 and 4) n=86	Inadequate adherers (score 0 and 2) n=30	P value	OR (95% C.I.) of being an adequate adherer[1]	P value
Coeliac Symptom Index	32.0 (9.8)	39.7 (10.9)	**<0.001**	0.93 (0.89 - 0.97)	**<0.001**	35.0 (11.0)	38.2 (11.0)	0.179	0.97 (0.94 - 1.01)	0.176
QoL										
Coeliac Disease Questionnaire										
Emotional wellbeing	36.7 (4.3)	31.7 (6.6)	**<0.001**	1.19 (1.09 - 1.30)	**<0.001**	34.8 (5.9)	32.4 (6.4)	0.059	1.07 (1.00 - 1.14)	0.064
Worries	42.5 (4.8)	38.3 (8.3)	**0.001**	1.10 (1.03 - 1.17)	**0.002**	41.2 (6.6)	37.9 (8.0)	**0.048**	1.06 (1.01 - 1.13)	**0.033**
Social	46.3 (4.7)	41.9 (7.6)	**<0.001**	1.15 (1.06 - 1.25)	**0.001**	44.7 (6.3)	42.4 (7.5)	0.094	1.05 (1.00 - 1.12)	0.108
Gastrointestinal	40.2 (6.9)	35.5 (8.3)	**0.001**	1.09 (1.03 - 1.15)	**0.002**	38.6 (8.0)	35.8 (7.5)	0.103	1.04 (0.99 - 1.10)	0.106
Total score	165.7 (15.5)	147.4 (26.6)	**<0.001**	1.04 (1.02 - 1.07)	**<0.001**	159.4 (22.0)	148.5 (26.3)	**0.029**	1.02 (1.00 - 1.04)	**0.035**

All data are mean (SD), unless otherwise indicated. "Ref" indicates the reference category against which the other categories within the variable are compared to. "-" indicates data generation was not applicable.

[1]Data generated from univariate logistric regression

[2]Lower scores denote stronger beliefs

Table 2: Comparison of demographic characteristics, knowledge, attitudes, experiences, symptoms and quality of life between those with adequate and inadequate adherence to a GFD, where adherence was measured using the Coeliac Dietary Adherence Test (CDAT) and Gluten Free Diet Score (GFD-S).

Subsequently, multivariable logistic regression was performed to identify the association between all factors and adherence to a GFD, measured using CDAT. Being female was associated with lower odds of adherence to GFD (OR 0.36, 95% CI 0.14-0.90; p=0.028), whereas having better emotional wellbeing was associated with greater odds of adherence to GFD (OR 1.19, 95% CI 1.09-1.30; p<0.001) (Figure 2). The model explained 28% (Nagelkerke R^2) of the variance in adhering to the GFD diet.
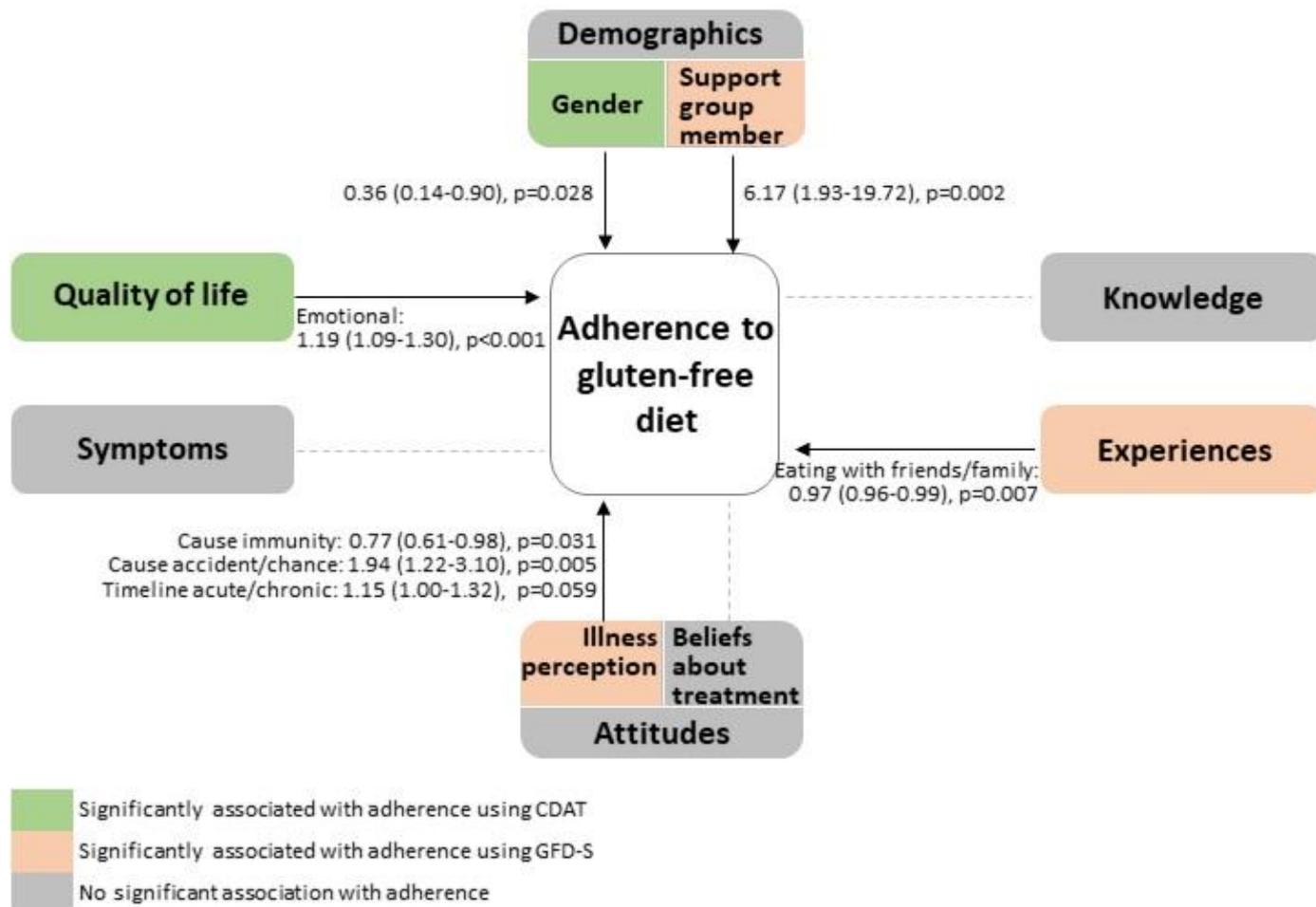

Figure 2: Multivariate logistic regression analysing the association between demographic characteristics, knowledge, attitudes, experiences, symptoms and quality of life with adherence to a gluten-free diet, where adherence was measured using the Coeliac Dietary Adherence Test (CDAT) and Gluten Free Diet Score (GFD-S) in 116 patients with coeliac disease. Data are presented as OR (95% CI). Variables highlighted in green represent those identified to be significantly associated with adherence to the GFD when this was measured using CDAT. Variables highlighted in orange represent those identified to be significantly associated with adherence to the GFD when this was measured using GFD-S. Variables

highlighted in grey were not significantly associated with adherence to the GFD when this was measured using CDAT or GFD-S.

When adherence was measured using GFD-S, a greater number of patients who were members of a support group for coeliac disease were adequate (n=54, 63%) than inadequate adherers (n=8, 27%; p=0.001), with being a member of a support group being associated with greater odds of adherence to the GFD (OR 4.64, p=0.001). A higher number of appointments with a gastroenterologist in the past 2 years was reported in adequate (mean 2.8, SD 2.4) than inadequate adherers (2.0, SD 1.7; p=0.037), however having more appointments with a gastroenterologist was not associated with adherence to the GFD in the univariate logistic regression analysis (OR 1.22, p=0.080). Better knowledge of the GFD was reported in adequate (mean 17.7, SD 5.3) than inadequate adherers (mean 15.5, SD 4.4; p=0.038), with having better knowledge being associated with greater odds of adherence to the GFD (OR 1.03, p=0.42).

Fewer challenges when preparing GF foods were reported in adequate (mean 27.3, SD 40.0) than inadequate adherers (mean 40.0, SD 31.2; p=0.049), with facing greater difficulties with preparing GF foods being associated with lower odds of adherence to the GFD (OR 0.98; p=0.027). Fewer challenges when eating with friends/family were also reported in adequate (mean 22.4, SD 24.5) than inadequate adheres (mean 37.3, SD 29.9; p=0.008), with facing greater challenges when eating with friends/family being associated with lower odds of adherence to the GFD (OR 0.98; p=0.11). Similarly, borderline fewer challenges when eating at school/university/work were reported in adequate (mean 19.9, SD 20.3) than inadequate adherers (mean 30.4, SD 26.6; p=0.055), with facing greater challenges when eating at school/university/work being associated with lower odds of adherence to the GFD (OR 0.98, p=0.031). Four illness-related attitudes (cause accident/chronic, timeline acute/chronic, illness coherence, and timeline cyclical) were associated with adherence to a GFD (Table 2). Age, gender, employment and symptoms were not associated with adherence to a GFD (Table 2).

Subsequently, multivariable logistic regression was performed to identify the association between all factors and adherence to a GFD, measured using GFD-S. Being a member of a support group (OR 6.17, 95% CI 1.93-19.72; p=0.002), and having stronger beliefs about the chronicity of coeliac disease (OR 1.15, 95% CI 1.00-1.32; p=0.059) and weaker beliefs on accident/chance being a cause of coeliac disease (OR 1.94, 95% CI 1.22-3.10; p=0.05) were associated with greater odds of adherence to a GFD. Experiencing difficulties with eating with

friends/family (OR 0.97, 95% CI 0.96-0.99; p=0.007) and having weaker beliefs on immunity being a cause of coeliac disease (OR 0.77, 95% CI 0.61-0.98; p=0.031) were associated with lower odds of adherence to the GFD (Figure 2). The model explained 42% (Nagelkerke R^2) of the variance in adhering to the GFD diet.

DISCUSSION

The aim of this study was to identify the relationship between adherence to a GFD and demographic characteristics, knowledge, attitudes and beliefs regarding coeliac disease and a GFD, experiences of following a GFD, symptoms and QoL. The results indicate that characteristics within all the main factors explored (demographics, knowledge, attitudes, experiences, symptoms and quality of life) were associated with adherence to a GFD when assessed separately, as has been shown previously[7,9]. However, what is novel in the current study is that when all these factors are assessed simultaneously in the multivariate regression analysis, only gender, attitudes towards coeliac disease, experiences following a GFD and emotional wellbeing remain independently associated with dietary adherence. Remarkably, there were also marked differences in the categorisation of patients as adherent depending upon the method used to measure and define adherence, and therefore the factors associated with adherence differed depending upon the method used.

Gender and membership of a coeliac patient support group were significantly associated with patient adherence to treatment, even after adjusting for knowledge, attitudes, experiences, symptoms and QoL, although results varied depending on the method of adherence assessment. Males were more likely to adhere to the GFD than females when measured by CDAT, but not when measured by GFS-D. A systematic review concluded that there is no consistent association between gender and adherence, however none of the studies were conducted in the UK and many did not adjust for a wide range of other factors[7]. A more recent large survey demonstrated that being male was an independent predictor of adherence to the GFD, as measured by CDAT, similarly to the findings of the current study [32]. More females (n=81) were recruited to the current study than males (n=31), although this might imply a gender bias in responses, given the overall high response rates and direct face-to-face recruitment strategy it more likely reflects the greater prevalence of coeliac diagnosis in females[33,34]. One study found that coeliac disease imposes greater burden for women than men, which could explain why females have poorer adherence[35], however in the present study experiences following a

GFD and QoL were adjusted for in the multivariate analysis. Interestingly, the findings of the current study agree with those reported in a previous study that analysed pharmacy and medical claims for 29.5 million adults and showed that women were less likely than men to adhere in their use of chronic medications[36]. In that study, women were also less likely to be monitored, for example through carrying out routine laboratory tests for their condition, which may reflect lower levels of self-care behaviour and/or treatment bias by healthcare professionals[36].

Members of a coeliac support groups consistently show greater adherence to GFD both in the current study and in previous studies[9,11]. There is likely to be a bi-directional association with membership being both a consequence and cause of improved adherence. For example, patients with coeliac disease who are more invested in their health, and thus maintain adhere strictly to the GFD, may be more motivated to join a coeliac support group. However, the emotional, social and educational support provided by coeliac support groups may assist members to improve their dietary adherence. Patients themselves recognise the importance of such support groups as 87% of coeliac support group members feel this involvement is beneficial[11]. Coeliac support groups may be potential targets for future interventions to support, educate and encourage patients.

Beliefs about the nature of coeliac disease were also significantly associated with adherence to a GFD in the multivariate analysis, when measured using GFD-S. Particularly, having weaker beliefs about the cause of coeliac disease being immune-related was associated with lower odds of adherence, while having weak beliefs about coeliac disease being caused by accident/chance was associated with greater odds of adherence. Having strong beliefs about the chronicity of the disease was also associated with greater odds of adherence to GFD. These patients are likely to have accepted that coeliac disease is not a temporary disease that will improve with time, and that lifelong treatment is required due to its chronicity. Such attitude towards the disease may emphasize its severity and ongoing need for treatment, and therefore motivate patients to adhere to a GFD to prevent long-term symptoms and complications.

The experiences and challenges faced by patients while following a GFD are also associated with their adherence. Facing greater difficulties when eating with friends/family was associated with poorer adherence, as measured by both CDAT and GFD-S. Importantly, facing greater difficulties when eating with family/friends was still significantly associated with poor adherence, even when adjusting for other factors in the multivariate analysis. This supports evidence from a previous study that emphasises the negative social impact of GFD, which is

the reason patients may avoid eating with others such as family, friends and colleagues, and instead shift to eating in private[9,37]. Support from family and friends is very important for patients following a GFD[38]. A team approach, including patients' family and friends, is required to support patients, but the effect of this support on dietary adherence is not identified [39]. Notably however, eating with family and friends was not associated with adherence in a previous study[16]. However, the methods to assess dietary adherence in that study was the frequency of intentional gluten consumption[16], which was different to the present study that used two validated adherence questionnaires. Not receiving gluten-free foods on prescription is another factor that has been previously associated with both poorer adherence and higher dietary burden of the GFD, highlighting the importance of prescriptions in adhering to a GFD[15,40].

Better quality of life was consistently associated with adhering to a GFD, when measured using both CDAT and GFD-S. Notably, emotional wellbeing was still associated with adherence, as measured by CDAT, after adjustment for other factors. The emotional wellbeing score represents the levels of depression, distress, happiness, and physical and emotional fatigue a patient experiences[29]. A previous study showed higher depression and anxiety in patients with villous healing compared to those with villous atrophy[41], however, other studies show lower depression and anxiety when adhering to the GFD[42,43]. Patients with poorer emotional wellbeing may feel overwhelmed and unable to cope with their diagnosis or GFD, and therefore may not adhere. This finding highlights the importance of assessing the emotional wellbeing of patients with coeliac disease and developing strategies to tackle emotional distress when identified.

Several factors were found to be individually associated with adherence to a GFD on the univariate analysis, although this association was no longer apparent in the multivariate analyses after adjusting for other factors. For instance, knowledge was associated with adherence to the GFD when this was measured using the GFD-S using univariate analysis, but not when measured using CDAT. However, when knowledge was analysed in the multivariate regression model, it was no longer associated with adherence to the GFD once adjusted for the other factors. This finding indicates that knowledge, when adjusted for demographic characteristics, attitudes, experiences, symptoms and QoL, no longer predicts adherence to a GFD. Interestingly, a recent systematic review concluded that knowledge of coeliac disease and GFD was one of the most important factors to determine adherence[9]. A previous study in 5,310 adults also showed that having better knowledge on the GFD was associated with

better adherence to GFD following adjustment for demographic characteristics, symptoms and psychological distress[44]. However, that analysis did not control for attitudes, experiences and QoL, which were all shown to be significant predictors of adherence in the current study. This finding suggests that attitudes, experiences and QoL may have a greater impact on patients' dietary behaviour than knowledge *per se*. Previous research has also suggested a lack of predictive power of knowledge in altering individual behaviour[45]. Therefore, although educating patients regarding coeliac disease and the GFD is a fundamental part of their care, this finding emphasizes the need to also assess and address other factors, such as attitudes, experiences and QoL, in order to support them in adhering to the GFD. It is also worth noting that one of the key sources of knowledge of the GFD is dietitians; however, input from dietitians varies considerably between countries and, thus, patients in different countries may receive different levels of education from dietitians, which will reflect on their knowledge of the GFD.

Experiencing fewer gastrointestinal symptoms was also associated with adherence to GFD, when measured using CDAT, a relationship that may be bi-directional and complex to interpret. Gluten-ingestion can affect patients differently as symptom severity depends upon levels of gluten exposure and is highly individual between patients. Patients who experience greater symptoms prior to diagnosis/treatment of coeliac disease may notice substantial relief of symptoms once they start a GFD, and will therefore be motivated to maintain treatment to avoid unwanted symptoms. Alternatively, those who experience fewer symptoms on gluten ingestion may not necessarily observe direct benefits from the GFD and, thus, have poorer adherence as they perceive gluten ingestion to be less harmful[46]. Nevertheless, symptoms did not predict adherence when adjusted for knowledge, attitudes, experiences and QoL, suggesting these other factors may be more prominent in determining adherence.

The factors identified as predictors of adherence to the GFD were different when the two separate methods were used to define adherence (CDAT and GFD-S). This may be explained by the fact that there was only a fair agreement on identifying adherence between the two methods; particularly, when adherence was measured using CDAT, 50% were adequate adherers, whereas when using GFD-S, 74% were adequate adherers. Varying adherence levels have also been demonstrated in previous studies, with a systemic review of 38 studies showing strict adherence ranges from 42% to 91%[7]. The lack of consensus regarding the definition of a strict GFD, as well as the use of different validated methods to measure it, may contribute to the wide range of adherence rates reported in the literature, as well as in the current study.

GFD-S was validated by comparing it to endomysial antibodies and to villous atrophy at duodenal biopsies, the latter being the only reliable methods to assess adherence to the GFD[22]. However, CDAT was validated by comparing it to dietitian evaluations and serology testing to confirm adherence[21], which is not considered a reliable indicator of adherence, thus posing questions regarding its validity to measure GFD adherence. In addition, the nature of the questions included in CDAT and GFD-S differed; GFD-S focuses on gluten ingestion only (e.g. "do you check labels of packaged food")[22], whereas CDAT also includes questions related to physical wellbeing (e.g. "have you been bothered by headaches"), attitudes (e.g. "how important to your health are accidental gluten exposures"), and personality characteristics (e.g. "before I do something, I carefully consider the consequences", "I do not consider myself a failure")[21]. It may therefore be possible that the adherence score calculated by CDAT is also affected by factors not related to the GFD *per se*, such as other medical conditions, depression and self-esteem. Nevertheless, a recent study that compared adherence scores from both CDAT and GFD-S questionnaires with duodenal biopsies revealed that CDAT had 52% sensitivity, whereas GFD-S had a much lower sensitivity of 22% [47]. It is therefore possible that CDAT may be a more appropriate tool in identifying adherence in people with coeliac disease. Finally, other adherence tools are currently being developed to evaluate adherence to the GFD, including a scoring system specifically aimed to be provided by dietitians[48].

Strengths and limitations

The strengths of this study include the face-to-face recruitment from outpatient clinics and thus high response rate and limited response bias. In addition, validated questionnaires where used to assess adherence to GFD, knowledge, attitudes, symptoms and QoL. In terms of limitations, the questionnaires used to assess knowledge and experiences have not been previously validated, but were used from previous studies in the absence of validated questionnaires[11,16]. In addition, although considered to be the gold-standard for assessing adherence to GFD, intestinal biopsies were not used to define adherence in the current study as this method is invasive, burdensome to patients, and expensive; instead, validated questionnaires were used. Finally, since this is a cross-sectional study, it is impossible to determine causality of these factors on adherence and nor is it possible to assess the direction of any relationship of adherence with demographic characteristics, knowledge, attitudes, experiences, symptoms and QoL.

Conclusion

To conclude, this study indicates that, when CDAT is used to define adherence, adherence is lower in females and higher in patients with better emotional wellbeing. When GFD-S is used to define adherence, it is higher in patients who are members of coeliac support groups and have strong beliefs about the chronicity and the immune-related cause of the disease, whereas adherence is lower in those experiencing difficulties with eating with friends/family and having strong beliefs on accident/chance being a cause of the disease. The significant associations between gender, attending support groups, attitudes towards coeliac disease, experiences following a GFD, and emotional wellbeing need to be considered by healthcare professionals when managing patients with coeliac disease. Further intervention trials are needed to examine whether altering or addressing these factors via additional education or support could improve adherence to the GFD.

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