The Association of UK Dietitians
THE OFFICIAL JOURNAL OF THE BRITISH DIETETIC ASSOCIATION
Journal of Human Nutrition and Dietetics

GASTROINTESTINAL DISORDERS

Healthcare experiences and quality of life of adults with coeliac disease: a cross-sectional study

H. Crocker C. Jenkinson & M. Peters

Nuffield Department of Population Health, University of Oxford, Headington, Oxford, UK

Keywords
coeliac disease, cross-sectional survey, healthcare services, patient experience, quality of life.

Correspondence
H. Crocker, Nuffield Department of Population Health, University of Oxford, Old Road Campus, Headington, Oxford, OX3 7LF, UK.
Tel.: 01865 289431
E-mail: helen.crocker@ndph.ox.ac.uk

How to cite this article
Crocker H., Jenkinson C. & Peters M. (2020) Healthcare experiences and quality of life of adults with coeliac disease: a cross-sectional study. *J Hum Nutr Diet*. **33**, 741–751
https://doi.org/10.1111/jhn.12757

Abstract

Background: Coeliac disease affects many aspects of quality of life and treatment can be burdensome. Access to healthcare services is necessary for the diagnosis and management of coeliac disease. The present study aimed to investigate the healthcare experiences of adults with coeliac disease and explore the relationship between experiences and quality of life.

Methods: A cross-sectional postal survey was sent to 800 members of Coeliac UK and contained questions about diagnosis, dietary advice, follow-up appointments, prescriptions, knowledge and information provision, and quality of life [Coeliac Disease Assessment Questionnaire (CDAQ)]. Descriptive statistics were calculated. A total problem score summarised the number of problems experienced with healthcare services. Multiple linear regression analyses were conducted to investigate experiential and demographic factors associated with quality of life.

Results: An average of 5.5 problems with healthcare services was reported, with females reporting significantly more problems than males (6.5 versus 5.0, $P = 0.003$). The total problem score was significantly related to the CDAQ overall index score and all CDAQ dimension scores (stigma, dietary burden, symptoms, social isolation, and worries and concerns) ($P < 0.001$). The analyses highlighted four key areas of healthcare experiences that were significantly related to quality of life: information provision, general practitioners' knowledge, communication with health professionals and access to prescriptions.

Conclusions: Poorer experiences of healthcare services in coeliac disease are related to worse quality of life. Improving services in the four key areas identified may help adults with coeliac disease to achieve a better quality of life.

Introduction

Coeliac disease is a chronic autoimmune condition in which the immune response is triggered by the consumption of gluten, a protein found in wheat, barley and rye. The prevalence of coeliac disease in the UK and Europe is approximately 1% (1,2,3), with studies estimating that many more people are living with undiagnosed coeliac disease (2,4,5). The only current treatment is a lifelong gluten-free diet (6), which can be challenging, particularly when eating outside of home and at work (7). The burden of following a gluten-free diet is comparable to or greater than the treatment burden of chronic conditions such as hypertension and end-stage renal disease (8). Coeliac disease can impact many aspects of quality of life, including emotional health, and daily and leisure activities (9). Furthermore, there is a small increased risk of malignancy and mortality compared to the general population (10,11), and an increased likelihood of developing other autoimmune diseases (12). Hence, it is important that people can access health services to diagnose and manage their condition.

In the UK, various bodies have developed guidelines for the diagnosis and management of coeliac disease, based on the best available evidence (13–17). For example, the National Institute for Health and Care Excellence

(NICE) guidelines state that people with coeliac disease should be offered an annual review, although they do not specify which health professional should conduct this (14). Furthermore, a Quality Standard (18) for coeliac disease sets out five key areas for healthcare improvement, including receiving dietary advice from a knowledgeable health professional. At the time of the study, people with coeliac disease were also supported with access to gluten-free foods on prescription. Prescriptions are free for those meeting eligibility criteria (e.g. 60 years or older), whereas others must pay prescription charges (currently £9 per prescription, or £104 for a 12-month prepayment certificate that covers all prescriptions received within that period). National guidelines outline the quantities and types of foods that can be prescribed (19). However, after the present study was completed, as a result of financial pressures on the National Health Service, access to prescriptions has been restricted or stopped in some geographical areas (20).

Asking patients about their healthcare experiences provides important information that allows providers and commissioners to assess whether guidelines are followed and standards met. Patient experience data focusing on the factual aspects of the processes of care allow areas for service improvement to be identified (21,22), whereas evaluations of care can help identify problematic aspects of healthcare that are most important to patients (23), or allow the acceptability of issues, such as waiting times, to be assessed (24). In England, the Government is committed to providing patients with a positive experience of care (25–26).

In coeliac disease, patient experience surveys have tended to focus on specific aspects of healthcare, such as follow-up (27), consultations with dietitians (28) and diagnosis (29). As far as we are aware, no studies have explored broader experiences of healthcare services (from diagnosis to follow-up), as investigated in, for example, neurological conditions (30). Research exploring the relationship between experiences and quality of life in coeliac disease has found significant associations between information provision and outcomes (31,32), although few studies have investigated this. The present study aimed to investigate patients' experiences of healthcare services in coeliac disease, from before diagnosis to the time of the survey, as well as explore the relationship between experiences of healthcare and quality of life.

Materials and methods

Study design

A cross-sectional postal survey of 800 members of Coeliac UK, a charity for people with coeliac disease, was conducted (September 2014). Members were eligible to participate if they were aged 18 years or older; lived in the UK; and self-reported a medical diagnosis of coeliac disease. To increase the likelihood of achieving a diverse sample, a random sample, stratified by ethnicity, age, and gender, were selected from Coeliac UK's membership database and invited to participate (for sampling strata, see Supporting information, Table S1). The number of respondents invited to participate was based on the assumption that a 30% response rate would be achieved, thus providing a sufficiently large sample on which to perform the analyses. The survey included the Coeliac Disease Patient Experience Questionnaire (developed for this study and described below) and demographic and disease-related questions (e.g. time since diagnosis, dietary adherence). The Coeliac Disease Assessment Questionnaire (CDAQ) (9,33) was also included and assesses health-related quality of life in adults with coeliac disease. It has 32 items addressing five dimensions: stigma; social isolation; symptoms; dietary burden; and worries and concerns. Dimension scores and an overall index score can be calculated (0–100), with higher scores indicating better quality of life. Ethics approval was obtained through the University of Oxford Central University Research Ethics Committee (Reference: MSD-IDREC-C1-2014-031).

The Coeliac Disease Patient Experience Questionnaire

The Coeliac Disease Patient Experience Questionnaire contains 53 questions about experiences of healthcare in relation to coeliac disease from pre- to post-diagnosis, which address diagnosis, dietary advice, follow-up appointments, prescriptions, and knowledge and information provision (for the questionnaire, see Supporting information, Appendix S1). Questionnaire items were derived from a thematic analysis of qualitative interviews with 23 adults with coeliac disease. The purpose of the interviews was two-fold: (i) to explore patients' experiences of healthcare services in relation to the diagnosis and management of coeliac disease and (ii) to understand how living with coeliac disease impacts on the health-related quality of life of adults, as reported elsewhere (9). Interviews were conducted until data saturation was reached. Details regarding participant recruitment and characteristics have been reported previously (9). Some minor adjustments to questions were made following a review of guidelines for the diagnosis and management of coeliac disease (13,15,17,34). Questionnaire items were systematically assessed and refined using the Question Appraisal System (QAS-99) (35) and reviewed by experts (healthcare professionals, researchers, and Coeliac UK employees). Finally, cognitive interviews (36,37) with 12 people with coeliac disease (round 1, *n* = 5; round 2, *n* = 7) were conducted to finalise the questionnaire. Two key issues identified from the cognitive interviews were the difficulty of capturing the diversity of experiences across respondents and respondents' difficulty in retrieving certain information relating to more distant events. Revisions to the questionnaire were made following each stage to address any issues identified (see Supporting information, Figure S1).

Analysis

Problem scores, missing data and summary variables

To analyse healthcare experience data, items were coded as dichotomous problem scores (i.e. 'no problem' = 0 or 'a problem' = 1) (Fig. 1), where a problem was considered by the patient to be an aspect of healthcare that could be improved upon (38). Certain items were unsuitable for coding as problem scores because they acted as filter questions or added context to answers of other questions (e.g. 'Who was your most recent follow-up appointment with?'). Thirty-one (of 53) items were coded as problem scores.

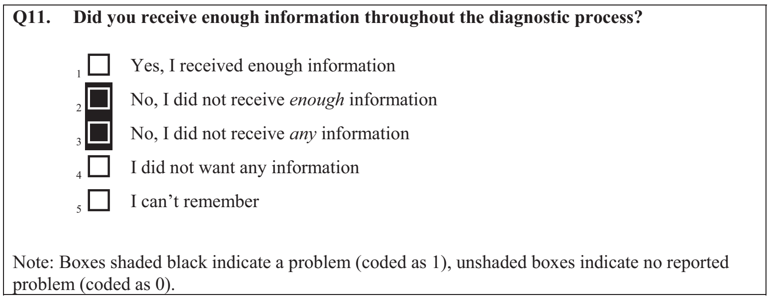
Missing data as a result of a nonresponse were low (<4%) with the exception of two items, 'not offered a blood test to diagnose coeliac disease' (14.2%) and 'pneumococcal vaccination not offered' (10.1%) (see Supporting information, Table S2). Furthermore, 'skipped data' occurred as a result of skip patterns in the questionnaire (i.e. respondents were instructed not to complete certain questions if deemed not applicable based on previous answers) (see Supporting information, Table S2). Missing and skipped data were coded as 'no problem' based on the assumption, as adopted in other patient experience surveys (38), that (i) any problems occurring would have been reported, and (ii) if questions were not relevant, individuals could not have experienced problems with those aspects of care.

A *total problem score* was created to explore how experiences varied between respondents and investigate associations with quality of life. Not all questions were relevant to all respondents, and therefore a sum of items could result in bias in the total problem score (i.e. those receiving fewer services may achieve lower total problem scores). To minimise bias, dichotomous summary variables for dietary advice and follow-up care were created (i.e. 'no problems' = 0 or 'one or more problems' = 1), and two remaining items where missing and skipped data totalled ≥20% were excluded from the total problem score. The total problem score was the sum of problems for the remaining dichotomised items and summary variables (0–21), where a higher score indicates a greater number of problems. In summary, 29 of 31 dichotomised problem scores contributed towards the total problem score (see Table 1).

Statistical analysis

Descriptive frequencies and proportions were calculated to show respondents' overall experience of healthcare services. Proportions are presented as the 'number of people affirming an item/number of people who were asked the question'. Associations between CDAQ scores and the total problem score were assessed using Pearson's correlation coefficients.

Bivariate analyses were conducted to explore the relationship between the total problem score and gender, ethnicity, age, time since diagnosis, number of comorbidities, gluten consumption and marital status. Number of comorbidities was calculated as the sum of comorbidities that the respondent selected from a list of conditions associated with coeliac disease, plus any additional self-reported medical conditions. Chi-squared was used to explore differences in follow-up between those diagnosed for less than 10 years, and for those diagnosed for 10 years or more. Backwards stepwise multiple linear regression analyses were conducted to explore the association between quality of life (CDAQ overall index score or dimension scores) and experiences of healthcare services ('total problem score' or dichotomised experience items). Included as potential confounders were: age, years since diagnosis, number of comorbidities, gender, ethnicity, marital status and gluten consumption. Regression coefficients for significant variables are shown in tables.



Q11. Did you receive enough information throughout the diagnostic process?

1 ☐ Yes, I received enough information
2 ■ No, I did not receive *enough* information
3 ■ No, I did not receive *any* information
4 ☐ I did not want any information
5 ☐ I can't remember

Note: Boxes shaded black indicate a problem (coded as 1), unshaded boxes indicate no reported problem (coded as 0).

Figure 1 An example of coding experience questions as problem scores.

$P < 0.05$ (two-sided) was considered statistically significant for all analyses. Data were analysed using SPSS, version 20 (IBM Corp., Armonk, NY, USA).

Results

Characteristics of study participants

Two hundred and seventy-six (34.5%) questionnaires were returned. Eight respondents were excluded from the analysis as they had not received a medical diagnosis. The majority of respondents were female (61.9%), married (59.3%), working (55.2%), white British (84.0%) and had not purposefully consumed gluten within the past 12 months (72.0%). Respondents had a mean (SD) age of 49.5 (18.9) years and had been diagnosed for a mean (range) of 7.5 (1–50) years, of which approximately 50% were diagnosed within the past 4 years (see Supporting information, Table S3).

Descriptive statistics

Diagnosis

The majority of respondents (93.3%, $n = 250/268$) received a diagnosis of coeliac disease aged 16 years or older, with 97.6% ($n = 244/250$) experiencing symptoms prior to diagnosis. On average, respondents received their diagnosis 4.0 years (range <1–50 years) after first seeking medical advice about their symptoms, with many reporting the time to diagnose as fairly or very slow (48.0%, $n = 110/229$). The majority had (94.0%, $n = 235/250$) or were offered (1.2%, $n = 3/250$) an endoscopy to diagnose their coeliac disease, with 12.8% ($n = 32/250$) reporting waiting times as slow. Most (88.8%, $n = 222/250$) were informed of their diagnosis by a hospital doctor/consultant or their general practioner (GP), with 26.4% ($n = 66/250$) reporting their diagnosis was communicated in a somewhat unprofessional or inappropriate manner. Some felt they did not receive enough information throughout the diagnostic process (20.0%, $n = 50/250$) or at the time of diagnosis (27.6%, $n = 69/250$).

Prior to diagnosis, most respondents spoke to a GP (70.3%, $n = 161/229$) or a hospital doctor/consultant (21.8%, $n = 50/229$) the most often. One-fifth reported that they lacked confidence in this health professional (21.8%, $n = 50/229$), that they did not feel their symptoms were taken seriously (20.5%, $n = 47/229$) or that the professional did not listen carefully (16.2%, $n = 37/229$).

Dietary advice

After diagnosis, 92.4% ($n = 231/250$) had a consultation with a dietitian, although a few reported no access to a dietitian when needed (3.6%, $n = 9/250$) or that access was slow (21.6%, $n = 50/231$). The majority (82.7%, $n = 191/231$) found their initial appointment helpful. Some (17.3%, $n = 40/231$) did not receive a second dietetic appointment but would have liked one.

Follow-up appointments

More than one-half (59.3%, $n = 159/268$) reported receiving follow-up appointments, with the majority (94.3%, $n = 150/159$) seen within the past 2 years. Receipt of follow-up care was not significantly associated with time since diagnosis ($P = 0.055$). Most appointments were with a hospital doctor/consultant (46.5%, $n = 74$), GP (20.8%, $n = 33$) or dietitian (18.9%, $n = 30$). Follow-up appointments most frequently involved (i.e. more than 50% reported) blood tests (78.0%, $n = 124/159$), being weighed (69.8%, $n = 111/159$) and the discussion of symptoms (55.3%, $n = 88/159$). Few (<25%) reported a discussion around food labelling (11.3%, $n = 18/159$), an assessment of emotional well-being (17.6%, $n = 28/159$) or a review of prescriptions (21.4%, $n = 34/159$). Respondents generally found appointments helpful (84.3%, $n = 134/159$). Of those not in receipt of follow-up care, 17.2% had been diagnosed within the past year and therefore the opportunity for follow-up may not yet have arisen.

The majority (84%, $n = 225/268$) wanted follow-up appointments in the future, with those diagnosed within the past 10 years more likely to want follow-up appointments than those diagnosed for 10 years or more (88.4% compared to 77.0%, $P = 0.021$). The preferred choice was to receive annual appointments (60.4%, $n = 136/225$) with a hospital doctor or consultant (48.4%, $n = 109/225$). One-quarter were not receiving follow-up appointments when they would have liked to (25.4%, $n = 68/268$).

Prescriptions

Prescriptions for gluten-free food were obtained by 70.1% ($n = 188/268$) of respondents during the past 12 months, with the most commonly prescribed items being bread or rolls (61.6%, $n = 165$), pasta (42.9%, $n = 115$), and flour or bread mixes (41.4%, $n = 111$). Of those receiving prescriptions, 65.4% ($n = 123$) were entitled to free prescriptions. Of those who pay for their prescriptions, 47.7% ($n = 31/65$) considered the cost ‘fairly’ or ‘very’ expensive. One-third (30.2%, $n = 81/268$) felt they had not received enough information about obtaining gluten-free food on prescription, with 20.1%, ($n = 54/268$) describing the process as ‘difficult’.

Knowledge and information provision

Many respondents perceived that GPs weren’t always knowledgeable about coeliac disease (66.4%, $n = 178/268$) or did not have a good understanding of the condition

(42.5%, *n* = 114/268). Fewer people felt dietitians (19.0%, *n* = 51/268) or specialist hospital doctors (10.8%, *n* = 29/268) lacked this knowledge. In the past 12 months, 67.5% (*n* = 181/268) had spoken to a health professional specifically about coeliac disease, of whom 41.0% (*n* = 110) consulted their GP, 38.4% (*n* = 103) a hospital doctor/consultant and 29.1% (*n* = 78) a dietitian. Some (30.6%, *n* = 82/268) were not always able to get the information and advice needed. When information was received, 16.4% (*n* = 44) reported problems with its consistency.

Problem scores and their relationship to quality of life

The number of respondents reporting problems with healthcare services is shown in Table 1. Respondents reported an average of 5.5 problems [interquartile range (IQR) = 3–10; range 0–19], with females (6.5, IQR = 3–10, *n* = 166) reporting significantly more problems than males (5.0, IQR = 2–8, *n* = 97, $P = 0.003$). Single respondents reported significantly more problems than those who were married or in a civil partnership ($P = 0.005$). An increase in the total problem score was significantly associated with younger age ($r_s = -0.39$, $P < 0.001$) and a shorter time since diagnosis ($r_s = -0.16$, $P = 0.01$). No significant differences in the total problem score were found by number of comorbidities, ethnic group, and self-reported frequency of gluten consumption.

An increase in the number of problems with healthcare services were significantly related to greater stigma ($r = -0.48$, $P < 0.001$), increased dietary burden ($r = -0.35$, $P < 0.001$), more symptoms ($r = -0.39$, $P < 0.001$), greater social isolation ($r = -0.48$, $P < 0.001$), more worries and concerns ($r = -0.45$, $P < 0.001$), and worse overall quality of life ($r = -0.51$, $P < 0.001$). Mean CDAQ scores are provided in the Supporting information (see Supporting information, Table S4), with further details, such as differences between groups, available elsewhere (33).

Regression analysis

Association between total problem score and quality of life

The total problem score was significantly related to the CDAQ overall index score ($P < 0.001$) after adjusting for confounding factors (Table 2). The relationship between total problem score and CDAQ dimensions were all significant ($P < 0.001$) (see Supporting information, Table S5).

Association between individual experience items and quality of life

Healthcare experiences that were significantly related to lower CDAQ overall index scores are shown in Table 3. Healthcare experiences and demographic factors significantly associated with CDAQ dimensions are shown in Table 4. The consistency and provision of information and advice were strongly related to all dimensions. Communication with health professionals was significantly related to stigma, social isolation, and worries and concerns. Difficulty obtaining prescriptions was significantly related to dietary burden and social isolation. Respondents' perceptions of GPs' knowledge was significantly related to dietary burden. Furthermore, a lack of confidence in the health professional seen most often prior to diagnosis, usually a GP, was related to stigma.

Discussion

Asking people about their experiences of health services can provide valuable information to guide the improvement of services (39). Furthermore, exploring the relationship between experiences of healthcare and quality of life highlights key aspects for service improvement that are most likely to result in quality of life gains. The present study aimed to identify problems with healthcare experiences of people with coeliac disease and investigate the relationship between healthcare experiences and quality of life.

This research found moderate to strong correlations between experiences of health services and quality of life, with problems found in four key areas: (i) the consistency and provision of information; (ii) perceived knowledge of GPs; (iii) communication with health professionals; and (iv) difficulties obtaining prescriptions. A strong relationship between the consistency and provision of information and quality of life is consistent with a German study (31) reporting that dissatisfaction with information provided by doctors was predictive of reduced quality of life. In the present study, quality of life was also related to the accessibility and quality of dietary advice. Although most respondents were able to see a dietitian following diagnosis, for some access was slow, an issue identified to a greater extent in a Finnish study (32). Respondents reporting slow or no access to a dietitian reported worse quality of life. Coeliac disease requires significant dietary changes, and therefore, to maximise quality of life, it is important that people receive adequate information about the gluten-free diet, particularly at the point of diagnosis. Because dietetic service provision has been previously found to be insufficient (40), alternative methods of information provision should be explored, for example, dietitian-led group clinics (41), and web-based and mobile technologies (such as those developed for Chronic Obstructive Pulmonary Disease (42)).

Poor information provision from GPs could in part be explained by the perception of many respondents (66.4%) that GPs lack knowledge of coeliac disease. Similarly, a

Table 1 Respondents reporting problems with healthcare services (n = 268)

Healthcare experience	Respondents reporting problems *n*	Respondents reporting problems %*	Contributed to total problem score?[†]
Diagnosis			
Felt their diagnosis of coeliac disease was slow	110	41.0	Yes
Health professional did not always inspire confidence	105	39.2	Yes
Health professional did not always listen carefully	98	36.6	Yes
Health professional did not always take symptoms seriously	94	35.1	Yes
Did not receive enough information at time of diagnosis	69	25.7	Yes
Informed of diagnosis in a somewhat unprofessional or inappropriate manner	66	24.6	Yes
Did not receive enough information throughout diagnostic process	50	18.7	Yes
Slow wait to receive an endoscopy	32	11.9	Yes
Not offered blood test to diagnose coeliac disease	8	3.0	–
Not offered an endoscopy to diagnose coeliac disease	4	1.5	Yes
Dietary advice			
Dietary advice summary score[‡]	99	36.9	Yes
Slow access to see dietitian following diagnosis	50	18.7	–
Not offered second appointment with dietitian when needed	40	14.9	–
Unhelpful first dietetic appointment	36	13.4	–
No access to dietitian following diagnosis when needed	9	3.4	–
Follow-up appointments			
Pneumococcal vaccination not offered	141	52.6	Yes
Follow-up summary score[‡]	116	43.3	Yes
Follow-up appointments not occurring (but individual would like to have follow-up)[§]	68	25.4	–
Questions at follow-up appointment not always answered adequately	31	11.6	–
Unhelpful follow-up appointment	23	8.6	–
Regular follow-up is infrequent	8	3.0	–
No opportunity to ask questions at follow-up appointment	5	1.9	–
Prescriptions			
Expensive cost of prescriptions	31	11.6	–
Not given enough information about prescriptions	81	30.2	Yes
Difficulties obtaining prescriptions	54	20.1	Yes
Knowledge and information			
Felt GPs weren't always knowledgeable about coeliac disease	178	66.4	Yes
GP did not always have good understanding of coeliac disease	114	42.5	Yes
Information and advice not always available from health professional when needed	82	30.6	Yes
Not given enough information about medical test results	78	29.1	Yes
Felt dietitians lacked knowledge about coeliac disease	51	19.0	Yes
Health professionals provided inconsistent information and advice	44	16.4	Yes
Felt specialist hospital doctors lacked knowledge about coeliac disease	29	10.8	Yes

GP, general practitioner.

*Percentage of respondents reporting problems calculated as a proportion of the whole sample (n = 268).

[†] Indicates whether the item contributed towards the total problem score.

[‡] The follow-up and dietary advice summary scores are dichotomous variables where 0 = 'no problems' and 1 = 'one or more problems' based on whether problems were reported in the individual follow-up and dietary advice items.

[§] Two items were combined to create this dichotomised problem score.

Finnish study (32) identified a key priority for patients was the improvement of physicians' knowledge. GPs are typically the primary point of contact prior to diagnosis, and therefore a lack of knowledge may contribute to lengthy diagnostic delays (43,44). GPs are also frequently consulted following diagnosis, including for annual review (17). Therefore, initiatives aimed at increasing awareness and knowledge of coeliac disease among GPs are needed; for example, through training and the modification of IT systems to support GPs with diagnosis and management (45).

Difficulty obtaining prescriptions was significantly related to quality of life, specifically dietary burden and social isolation. Fewer respondents (70.1%) reported obtaining gluten-free food on prescription than a previous UK study (89%, n = 111) (27). Almost one-third (30.2%) felt they had not been given enough information

Table 2 Multiple linear regression analysis of factors associated with Coeliac Disease Assessment Questionnaire (CDAQ) overall index score, with 'total problem score' as an independent variable

Dependent variable	Unstandardised coefficients				
Independent variables	*b*	SE (*b*)	β	*t*	*P*
CDAQ overall index score					
Constant	56.79				
Age	0.19	0.056	0.20	3.38	0.001
Male	6.04	1.98	0.16	3.05	0.003
No of comorbidities	−2.87	0.68	−0.23	−4.20	<0.001
Black and minority ethnicities	−6.47	2.91	−0.11	−2.23	0.027
Total problem score	−1.49	0.22	−0.37	−6.64	<0.001

Table includes significant variables only, adjusted r^2 = 0.37, $P < 0.001$.

Table 3 Multiple linear regression analysis of factors associated with Coeliac Disease Assessment Questionnaire (CDAQ) overall index score, with dichotomous experience items as independent variables

Dependent variable	Unstandardised coefficients				
Independent variables	*b*	SE (*b*)	β	*t*	*P*
CDAQ overall index score					
Constant	52.49				
Age	0.17	0.58	0.17	2.83	0.005
Male	8.01	2.06	0.21	3.90	<0.001
No of comorbidities	−2.68	0.72	−0.21	−3.73	<0.001
Years since diagnosis	0.23	0.11	0.11	2.09	0.038
Black and minority ethnicities	−7.16	2.98	−0.13	−2.40	0.017
Health professional did not listen	−6.40	2.04	−0.17	−3.14	0.002
Difficulties obtaining prescriptions	−5.71	2.44	−0.13	−2.35	0.020
Inconsistent information and advice	−7.01	2.60	−0.15	−2.70	0.008
Dietary advice score	−5.05	2.02	−0.14	−2.50	0.013

Table includes significant variables only, adjusted r^2 = 0.37, $P < 0.001$.

about prescriptions. People are likely to benefit from receiving clearer information about prescriptions and the prescribing process at diagnosis and follow-up. This is particularly important because prescribing policies at a local level have not always been consistent with national guidance (20), as well as with the introduction of new policies (46).

Further to the four key areas identified above, many respondents reported problems with follow-up care, such as not receiving appointments. These findings support those of another UK study (27) (62.0% received follow-up compared with 59.3% in the present study). The NICE guidelines (14) and quality standard for coeliac disease (18) both state that people should be offered an annual review, and therefore access to follow-up needs to be improved. For those receiving follow-up care, emotional well-being was rarely assessed (17.6%). Because there is a relationship between coeliac disease and mental health problems such as depression and anxiety (47–49), assessing emotional well-being as part of review appointments could help to reduce mental health problems in this population.

There are some limitations to the present study. A cross-sectional design means causality cannot be determined. However, the data appear to suggest that poorer experiences of services lead to poorer quality of life, or those with poorer quality of life are not getting the support that they need, or a combination of these factors. Either way, it follows that improving health services is likely to result in improvements to quality of life. Presenting patients' experiences as dichotomous problem scores is common with experiential data (30,38); however, the proportions reported for questions not relevant to all respondents are likely to be conservative estimates. As such, although problem scores are a useful way of summarising patients' experiences to provide an indication of what we know to be a problem, they may be an underestimate. Furthermore, the calculation of a 'total problem score' assumes that all reported problems are equal.

Table 4 Multiple linear regression analysis of factors associated with Coeliac Disease Assessment Questionnaire (CDAQ) dimension scores, with dichotomous experience items as independent variables

Dependent variable	Unstandardised coefficients				
Independent variables	*b*	SE (*b*)	β	*t*	*P*
CDAQ stigma score					
Constant	40.87				
Age	0.38	0.06	0.34	6.16	<0.001
Male	6.95	2.36	0.16	2.95	0.004
No of comorbidities	−2.66	0.81	−0.18	−3.29	0.001
Informed of diagnosis unprofessionally	−7.01	2.60	−0.14	−2.70	0.008
Inconsistent information and advice	−11.83	2.97	−0.21	−3.99	<0.001
Lack of confidence in health professional	−5.83	2.33	−0.13	−2.51	0.013
CDAQ dietary burden score					
Constant	43.87				
Male	5.95	2.37	0.15	2.51	0.013
Years since diagnosis	0.41	0.13	0.19	3.27	0.001
Consumes gluten					
Never	*Reference*				
Rarely	−3.12	3.08	−0.06	−1.01	0.312
Sometimes	−7.81	3.75	−0.12	−2.08	0.038
Often or always	−20.44	7.81	−0.15	−2.62	0.009
Difficulties obtaining prescriptions	−5.56	2.78	−0.12	−2.00	0.047
Information and advice not available	−5.84	2.51	−0.14	−2.33	0.021
GPs lack knowledge of coeliac disease	−5.20	2.60	−0.13	−2.00	0.047
Dietary advice score	−4.81	2.38	−0.12	−2.02	0.045
CDAQ symptoms score					
Constant	53.89				
Age (years)	0.33	0.07	0.26	4.53	<0.001
Male	9.72	2.73	0.19	3.56	<0.001
Black and minority ethnicities	−10.72	4.15	−0.14	−2.58	0.010
Consumes gluten					
Never	*Reference*				
Rarely	−0.47	3.57	−0.01	−0.13	0.894
Sometimes	−9.91	4.31	−0.12	−2.30	0.022
Often or always	15.24	9.58	0.09	1.59	0.113
No of comorbidities	−4.86	0.94	−0.29	−5.16	<0.001
Inconsistent information and advice	−7.96	3.57	−0.12	−2.23	0.027
Dietary advice score	−8.82	2.74	−0.18	−3.22	0.001
CDAQ social isolation score					
Constant	69.44				
Age (years)	0.22	0.07	0.18	3.10	0.002
Male	5.18	2.60	0.11	1.99	0.047
No of comorbidities	−3.60	0.91	−0.22	−3.97	<0.001
Health professional did not listen	−11.21	2.61	−0.24	−4.29	<0.001
Not enough information throughout diagnosis	−8.62	3.21	−0.15	−2.69	0.008
Difficulties obtaining prescriptions	−6.65	3.15	−0.12	−2.11	0.036
Information and advice not available	−7.13	2.81	−0.14	−2.54	0.012
CDAQ worries and concerns score					
Constant	46.15				
Age (years)	0.25	0.07	0.22	3.68	<0.001
No of comorbidities	−2.44	0.85	−0.17	−2.87	0.005
Consumes gluten					
Never	*Reference*				
Rarely	7.23	3.29	0.13	2.20	0.029
Sometimes	4.89	4.02	0.07	1.22	0.224
Often or always	4.49	8.63	0.03	0.52	0.603

Table 4 Continued

Dependent variable Independent variables	Unstandardised coefficients *b*	SE (*b*)	β	*t*	*P*
Information and advice not available	−5.63	2.81	−0.13	−2.01	0.046
Inconsistent information and advice	−6.92	3.38	−0.12	−2.05	0.042
Informed of diagnosis unprofessionally	−6.62	2.86	−0.14	−2.32	0.021
Dietary advice	−5.45	2.55	−0.13	−2.14	0.033

Table includes significant variables only.

Adjusted r^2 values - CDAQ stigma (0.34), CDAQ dietary burden (0.20), CDAQ symptoms (0.31), CDAQ social isolation (0.31), CDAQ worries and concerns (0.21), all $P < 0.001$.

GP, general practitioner.

However, certain problems may be perceived by respondents as more bothersome than others, yet this may vary between respondents. As such, a sum of problematic experiences provides a good estimate and is common practice in the literature. Survey respondents were all members of Coeliac UK and therefore it is possible that this population differs from the wider population of people with coeliac disease, although we are not aware of any evidence to support this. Finally, the survey achieved a response rate of 34.5%. Although similar to other studies (44), the results should be interpreted with caution because they may not be representative of the full population of people with coeliac disease.

This research is the most comprehensive study of patients' experiences of healthcare services in coeliac disease. The study has identified four key areas (information provision, GPs' knowledge, communication with health professionals and access to prescriptions) in which service improvements are most likely to result in quality of life gains for adults with coeliac disease.

Transparency declaration

The lead author confirms that this manuscript is an honest, accurate, and transparent account of the study being reported. The reporting of this work is compliant with STROBE guidelines. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

Acknowledgments

We thank the members of Coeliac UK for participating in the survey, as well as the experts and people with coeliac disease for their views on the survey questions developed. We also thank Coeliac UK for their support with recruitment.

Conflict of interests, source of funding, authorship

HC, CJ and MP are developers and copyright holders of the Coeliac Disease Assessment Questionnaire (CDAQ) which is licensed through Oxford University Innovation Ltd.

HC and the research were funded as a DPhil student by the Medical Research Council (MRC), UK. MP was funded by the Policy Research Programme (PRP) in the Department of Health and Social Care England, which supported the Quality and Outcomes of Person-centred Care Policy Research Unit (QORU). The views expressed are those of the authors and not necessarily those of the MRC or the Department of Health and Social Care.

All authors contributed to the conception and design of the study. All authors were involved in the development of the survey. HC collected and processed the survey data. HC led the analysis of survey data, with the support of CJ and MP. HC led on drafting the manuscript with input from CJ and MP. All authors have critically reviewed and approved the final version of the manuscript submitted for publication.

References

1. Mustalahti K, Catassi C, Reunanen A *et al.* (2010) The prevalence of celiac disease in Europe: results of a centralized, international mass screening project. *Ann Med* **42**, 587-595.
2. van Heel DA & West J (2006) Recent advances in coeliac disease. *Gut* **55**, 1037-1046.
3. Singh P, Arora A, Strand TA *et al.* (2018) Global prevalence of coeliac disease: systematic review and meta-analysis. *Clin Gastroenterol Hepatol* **16**, 823-836.
4. West J, Otete H, Sultan AA *et al.* (2019) Changes in testing for and incidence of celiac disease in the United Kingdom: a population-based cohort study. *Epidemiology* **30**, e23-e24.
5. Coeliac UK (2018). Coeliac Disease Diagnosis Rises to 30% - But Still Missing Half a Million. https://www.coeliac.org.uk/document-library/5437-coeliac-disease-diagnosis-rises-to-30-but-still-missing-half-a/ (accessed February 2019).

6. Green PH & Cellier C (2007) Celiac disease. *N Engl J Med* **357**, 1731-1743.
7. Sverker A, Hensing G & Hallert C (2005) 'Controlled by food'- lived experiences of coeliac disease. *J Hum Nutr Diet* **18**, 171-180.
8. Shah S, Akbari M, Vanga R *et al.* (2014) Patient perception of treatment burden is high in celiac disease compared with other common conditions. *Am J Gastroenterol* **109**, 1304-1311.
9. Crocker H, Jenkinson C & Peters M (2018) Quality of life in coeliac disease: qualitative interviews to develop candidate items for the Coeliac Disease Assessment Questionnaire. *Patient Relat Outcome Meas* **9**, 211-220.
10. Hopper AD, Hadjivassiliou M, Butt S *et al.* (2007) Adult coeliac disease. *BMJ* **335**, 558-562.
11. Quarpong W, Card TR, West J *et al.* (2019) Mortality in people with coeliac disease: long-term follow-up from a Scottish cohort. *United European Gastroenterol J* **7**, 377-387.
12. Malamut G & Cellier C (2015) Complications of coeliac disease. *Best Pract Res Clin Gastroenterol* **29**, 451-458.
13. National Institute for Health and Clinical Excellence (NICE) (2009) *Coeliac Disease: Recognition and Assessment of Coeliac Disease*. London: National Institute for Health and Clinical Excellence.
14. National Institute for Health and Clinical Excellence (NICE) (2009) *Coeliac disease: recognition, assessment and management*. London: National Institute for Health and Clinical Excellence. https://www.nice.org.uk/guidance/ng20 (accessed January 2020).
15. Ciclitira PJ, Dewar DH, McLaughlin SD*et al.* (2010). The Management of Adults with Coeliac Disease. http://www.bsg.org.uk/images/stories/clinical/bsg_coeliac_10.pdf (accessed September 2016).
16. Ludvigsson JF, Bai JC, Biagi F *et al.* (2014) Diagnosis and management of adult coeliac disease: guidelines from the British Society of Gastroenterology. *Gut* **63**, 1210-1228.
17. Primary Care Society for Gastroenterology (PCSG) (2006). The Management of Adults with Coeliac Disease in Primary Care. https://www.coeliac.org.uk/document-library/1464-primary-care-society-for-gastroenterology-2006/ (accessed January 2020).
18. National Institute for Health and Care Excellence (NICE) (2016). Coeliac Disease: Quality standard QS134. https://www.nice.org.uk/guidance/qs134 (accessed January 2020).
19. Coeliac UK in collaboration with The British Dietetic Association and the Primary Care Society for Gastroenterology (2011). Gluten-Free Foods: A Revised Prescribing Guide 2011. https://www.coeliac.org.uk/document-library/378-gluten-free-foods-a-revised-prescribing-guide/ (accessed 21 February 2020).
20. Kurien M, Trott N, Sleet S *et al.* (2018) Prescribing gluten-free foods in general practice. *Br J Gen Pract* **68**, 364-365.
21. Coulter A, Fitzpatrick R & Cornwell J (2009). The Point of Care: Measures of Patients' Experience in Hospital: Purpose, Methods and Uses. https://www.kingsfund.org.uk/sites/default/files/Point-of-Care-Measures-of-patients-experience-in-hospital-Kings-Fund-July-2009_0.pdf (accessed January 2020).
22. Sizmur S & Redding D (2009). Core Domains for Measuring Inpatients' Experience of Care. https://www.picker.org/wp-content/uploads/2014/10/Core-domains-for-measuring-inpatient-experience-of-care.pdf (accessed January 2020).
23. Fitzpatrick R (2002) Capturing what matters to patients when they evaluate their hospital care. *Qual Saf Health Care* **11**, 306.
24. Ahmed F, Burt J & Roland M (2014) Measuring patient experience: concepts and methods. *Patient.* **7**, 235-241.
25. Great Britain. Department of Health (2016). The NHS Outcomes Framework 2016–17. https://www.gov.uk/government/publications/nhs-outcomes-framework-2016-to-2017 (accessed January 2020).
26. NHS (2019). The NHS Long Term Plan. https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/ (accessed: January 2020).
27. Bebb JR, Lawson A, Knight T *et al.* (2006) Long-term follow-up of coeliac disease-what do coeliac patients want? *Aliment Pharmacol Ther* **23**, 827-831.
28. Mahadev S, Simpson S, Lebwohl B *et al.* (2013) Is dietitian use associated with celiac disease outcomes? *Nutrients* **5**, 1585-1594.
29. Nörstrom F, Lindholm L, Sandstrom O *et al.* (2011) Delay to celiac disease diagnosis and its implications for health-related quality of life. *BMC Gastroenterol* **11**, 118.
30. Peters M, Fitzpatrick R, Doll H *et al.* (2013) Patients' experiences of health and social care in long-term neurological conditions in England: a cross-sectional survey. *J Health Serv Res Policy* **18**, 28-33.
31. Häuser W, Stallmach A, Caspary WF *et al.* (2007) Predictors of reduced health-related quality of life in adults with coeliac disease. *Aliment Pharmacol Ther* **25**, 569-578.
32. Ukkola A, Mäki M, Kurppa K *et al.* (2012) Patients' experiences and perceptions of living with coeliac disease - implications for optimizing care. *J Gastrointestin Liver Dis* **21**, 17-22.
33. Crocker H, Jenkinson C & Peters M (2018) Quality of life in coeliac disease: item reduction, scale development and psychometric evaluation of the Coeliac Disease Assessment Questionnaire (CDAQ). *Aliment Pharmacol Ther* **48**, 852-862.
34. Bai JC, Fried M, Corazza GR *et al.* (2013) World Gastroenterology Organisation global guidelines on celiac disease. *J Clin Gastroenterol* **47**, 121-126.
35. Willis GB & Lessler JT (1999). Question Appraisal System QAS-99. https://www.researchgate.net/publication/267938670_Question_Appraisal_System_QAS-99_By (accessed January 2020).

36. Willis GB (1999). Cognitive Interviewing: A "How to" Guide'. http://appliedresearch.cancer.gov/archive/cognitive/interview.pdf (accessed August 2016).
37. Willis GB (2015) *Analysis of the Cognitive Interview in Questionnaire Design*. New York: Oxford University Press.
38. Jenkinson C, Coulter A & Bruster S (2002) The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. *Int J Qual Health Care* **14**, 353-358.
39. Coulter A (2006) Can patients assess the quality of health care? Patients' surveys should ask about real experiences of medical care. *Br Med J* **333**, 1-2.
40. Nelson M, Mendoza N & McGough N (2007) A survey of provision of dietetic services for coeliac disease in the UK. *J Hum Nutr Diet* **20**, 403-411.
41. Trott N, Kurien M, Branchi F *et al.* (2016) Comparing dietitian-led group clinics to individual appointments for newly diagnosed patients with coeliac disease (CD). *Gut* **65**, A292.
42. Bourne S, DeVos R, North M *et al.* (2017) Online versus face-to-face pulmonary rehabilitation for patients with chronic obstructive pulmonary disease: randomised controlled trial. *BMJ Open* **7**, e014580.
43. Gray AM & Papanicolas IN (2010) Impact of symptoms on quality of life before and after diagnosis of coeliac disease: results from a UK population survey. *BMC Health Serv Res* **10**, 105-112.
44. Violato M & Gray A (2019) The impact of diagnosis on health-related quality of life in people with coeliac disease: a UK population-based longitudinal perspective. *BMC Gastroenterol* **19**, 68.
45. Preest G (2016). Helping to Diagnose Coeliac Disease in Primary Care. https://www.coeliac.org.uk/research/our-approach/research-conference/research-conference-2016/day-2-diagnosis-and-management-of-coeliac-disease-time-for/helping-to-diagnose-coeliac-disease-in-primary-care-dr-geraint/?preview=true (accessed January 2020).
46. NHS England (2018). Prescribing Gluten-free Foods in Primary Care: Guidance for CCGs. https://www.england.nhs.uk/wp-content/uploads/2018/11/prescribing-gluten-free-foods-primary-care-guidance-for-ccgs.pdf (accessed January 2020).
47. Addolorato G, Capristo E, Ghittoni G *et al.* (2001) Anxiety but not depression decreases in coeliac patients after one-year gluten-free diet: a longitudinal study. *Scand J Gastroenterol* **36**, 502-206.
48. Ciacci C, Iavarone A, Mazzacca G *et al.* (1998) Depressive symptoms in adult coeliac disease. *Scand J Gastroenterol* **33**, 247-250.
49. Fera T, Cascio B, Angelini G *et al.* (2003) Affective disorders and quality of life in adult coeliac disease patients on a gluten-free diet. *Eur J Gastroenterol Hepatol* **15**, 1287-1292.

Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Figure S1. Number of items, and amendments made, at each stage of development of the Coeliac Disease Patient Experience Questionnaire.

Table S1. Strata used to sample Coeliac UK members for the survey.

Table S2. Number of respondents for which there is missing data as a result of a nonresponse or skip patterns.

Table S3. Characteristics of survey respondents (n = 268).

Table S4. Health-related quality of life in coeliac disease: CDAQ scores.

Table S5. Multiple linear regression analysis of factors associated with CDAQ dimension scores, with 'total problem score' as an independent variable.

Appendix S1. Experiences of healthcare services questionnaire.