RESEARCH PAPER

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

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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.

Figure 1 An example of coding experience questions as problem scores.
**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 practitioner (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 dietician, although a few reported no access to a dietician 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.
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...
A 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 1** Respondents reporting problems with healthcare services (n = 268)

| Healthcare experience                                                                 | Respondents reporting problems | Contributed to total problem score? |
|--------------------------------------------------------------------------------------|---------------------------------|-------------------------------------|
|                                                                                      | n     | %*                  |                                     |
| 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                |                                     |
| 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                | –                                   |
| Difficulties obtaining prescriptions                                                 | 54    | 20.1                | –                                   |
| 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.
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.

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 | | | | |
|------------------|-----------------------------|---|---|---|---|
| CDAQ overall index score | | | | | |
| Constant | 56.79 | 9.056 | 0.20 | 3.38 | 0.001 |
| 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 | | | | |
|------------------|-----------------------------|---|---|---|---|
| CDAQ overall index score | | | | | |
| Constant | 52.49 | 9.056 | 0.17 | 2.83 | 0.005 |
| 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 $r^2 = 0.37$, $P < 0.001$.
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 | 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 |       |
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.

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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.

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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.

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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.