Quality of Life in Coeliac Disease is Determined by Perceived Degree of Difficulty Adhering to a Gluten-Free Diet, not the Level of Dietary Adherence Ultimately Achieved

Stephen M. Barratt, John S. Leeds, David S. Sanders

The Gastroenterology & Liver Unit, The Royal Hallamshire Hospital, Sheffield Teaching Hospitals, NHS Foundation Trust, United Kingdom

Abstract

Background: Coeliac Disease (CD) is an increasingly common autoimmune condition, the treatment of which is a gluten-free diet (GFD). Previous studies fail to reach consensus of the impact this restrictive diet has on an individual's quality of life (QoL). Furthermore, how patient characteristics, such as demographic and educational background, may predict GFD adherence is poorly understood. We aimed to assess which factors had an impact on Qol in patients with CD. **Methods**: Case-control postal survey (n=573). Biopsy-proven CD patients (n=225; mean disease duration 8yrs; range 0.5-52yrs; male 26%) and age and sex matched controls (n=348; male 36%) completed The Short-Form 36-Item (SF-36) QoL measure, The Hospital Anxiety & Depression Scale (HADS), GFD assessment, and demographic questionnaire. **Results**: We found a high proportion of GFD adherence: 'Full Adherence' 65%, 'Partial Adherence' 31%, 'None Adherence' 4%, accompanied however, by 80% of patients reporting difficulty adhering to the GFD: 'Impossible' 5%, 'Mostly difficult' 14%, 'Sometimes difficult' 61%, 'No difficulty' 20%. Negligible differences in QoL scores were observed when comparing full versus partial/none GFD patients (P=>0.05), however, stepwise reductions in QoL and increasing likelihood of anxiety/depression were found in association with increasing degree of difficulty adhering to the GFD (P=<0.0001). Demographic assessment suggests that an affluent background and a university education promote greater GFD adherence. **Conclusions**: Most coeliac patients adhere to a GFD but encounter difficulty doing so (potentially influenced by social and educational background). The degree of GFD difficulty is associated with reductions in patient wellbeing and psychological distress that the dietician is critically placed to address.

Key words

Coeliac disease – quality of life – gluten-free diet – anxiety – depression – dietician.

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Address for correspondence: Stephen M. Barratt
The Gastroenterology & Liver Unit
The Royal Hallamshire Hospital
Sheffield Teaching Hospitals
NHS Foundation Trust
Sheffield S10 2JF, United Kingdom
Email: mdd06sb@sheffield.ac.uk

Introduction

To judge quality of life (QoL) is to engage in a highly subjective appraisal of the degree to which needs and expectations are fulfilled [1, 2]. Health-related QoL concerns the degree to which needs and expectations are affected by personal health. This includes physical and mental functioning, disability and the experience of symptoms [3]. Whilst difficult to conceptualise, QoL is of critical importance to patients and healthcare professionals and is emerging as a key outcome measure in today's 21st century healthcare system [4].

Coeliac Disease (CD) is a common autoimmune condition with an estimated prevalence of 1:100 [5] in which the only effective treatment is the gluten-free diet (GFD). This diet involves the wholesale and lifelong exclusion of gluten and, consequently, foods containing wheat, barley, rye and oats. These are major ingredients in the typical western diet.

The GFD's impact on QoL has served as the focus of international research with Canadian [6], German [7], British [8], American [9], and Italian [10] studies reporting negative associations between gluten-free living and QoL. In each study the principal discriminating factor between the coeliac participants has been their level of GFD adherence. In our opinion, whilst useful, such an outcome measure fails to tell the whole story of what it means to live with CD. It views gluten-free living as an end-product rather than, more accurately, a complex process of continual dietary vigilance and transactions in which the availability, choice and intake of non-toxic 'safe' food products are vitally important to health. Our view is, however, speculative and untested.

Therefore, we completed a QoL assessment in CD patients accounting for both the process (degree of difficulty adhering to the GFD) and end-product (level of GFD adherence ultimately achieved) of gluten-free living.

To support our findings we investigated the range of

social situations in which the GFD posed difficulty and to what extent patient characteristics (demographic, social and educational) are associated with poor treatment/GFD compliance. In doing so we hoped to refine our understanding of how gluten-free living is associated with QoL.

Materials and Methods

Participants

All CD patients (n=503) receiving out-patient follow up at The Gastroenterology & Liver Unit, The Royal Hallamshire Hospital (Sheffield, United Kingdom) received postal questionnaires. Members of the public accompanying family or friends to the out-patient complex at The Royal Hallamshire Hospital were invited to participate. These non-health seeking individuals were excluded from the study if they had, or were under investigation for, CD or had other dietary restrictions due to food allergy or intolerances. Being a vegetarian/vegan was not an excluding factor.

Written consent was obtained from all participants and ethical approval was granted by The National Health Service (NHS) North Sheffield Research Ethics committee in January 2009. All participants were over 18 years of age.

Quality of life and psychological wellbeing

The Short-Form 36-Item Health Survey [11] is a generic QoL measure composed of thirty-six questions forming eight subscales. Each subscale relates to a specific QoL domain: Physical Functioning (PF), Role-Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role-Emotional (RE), and Mental Health (MH). These subscales are further aggregated to form a Physical Component Summary (PCS) score and a Mental Component Summary (MCS) score.

The Hospital Anxiety and Depression Scale (HADS) [12] is a psychological screening tool composed of 14 questions. Seven relate to symptoms of anxiety (HADS-A) and seven relate to symptoms of depression (HADS-D). The likelihood of anxiety and depression is determined on the basis of each subscale score. For example, a HADS-A score of seven or below suggests the participant is unlikely to have anxiety, a score between eight and ten suggests possible anxiety, and a score of eleven or above suggests probable anxiety [13].

Dietary assessment

GFD adherence was categorised as 'Fully Adherent' (everyday of the previous twenty-eight days with no known dietary transgressions), 'Partially Adherent' (at least half of the days), and 'None Adherent' (none of the days) [7]. Over the same 28 day period patients rated the perceived degree of difficulty encountered adhering to the GFD: 'No difficulty', 'Sometimes difficult', 'Mostly difficult', or 'Impossible'. Furthermore, patients stated which lifestyle situations presented particular difficulty when adhering to a GFD: 'eating out', 'socialising', 'travelling', 'at work', 'at home', and 'in personal relationships'.

Demographic assessment

A broad demographic assessment composed of patient age, sex, marital status, and highest educational qualification held was completed by CD patients. Control subjects were required to complete a basic demographic assessment (age and sex).

Allocation of ACORN categories was made on receipt of each patient's postcode. These categories are 'Wealthy Achievers', 'Urban Prosperity', 'Comfortably Off', 'Moderate Means' and 'Hard Pressed'. ACORN (A Classification of Residential Neighbourhoods) is a geo-demographic tool based on UK census and lifestyle survey data. ACORN categorises 1.9 million UK postcodes on the basis of variables such as home ownership, affluence, deprivation and consumer spending habits and is used by government agencies and commercial enterprises. See http://www.caci.co.uk/acorn-classification.aspx for further details. Disease duration and patient method of presentation (MoP) (categorised as 'Typical': GI symptoms; 'Atypical': Non-GI symptoms; 'Screen-detected': Asymptomatic) were obtained from medical records.

Statistical analysis

When undertaking statistical analysis we used Mann-Whitney U tests to compare two groups and Kruskall-Wallis tests when comparing more than two groups. We used SPSS v15.0 for these tasks (IBM, Surrey, UK).

Results

Five hundred seventy-three completed questionnaires were received: 225/503 (44.7%) of invited CD patients (of whom 26% are male, mean disease duration is 8 years ranging from 6 months to 51 years) and 348/450 (77.3%) of invited control subjects (of whom 36% are male). We attribute the large discrepancy in response rates between the two groups to the difference in methods of participant recruitment; CD participants by post and potential control subjects face-to-face. Statistical analysis of patients and control subjects revealed no significant differences in terms of age or sex (Table I).

Table I. Descriptive statistics

	Controls (n=348)	Coeliac disease (n=225)	Significance
Demographics			
Age (% males)			
18-25 years	48 (36)	12 (16)	ns
26-35 years	30 (30)	8 (25)	ns
36-45 years	44 (47)	42 (15)	ns
46-55 years	65 (25)	44 (21)	ns
56-65 years	70 (40)	59 (26)	ns
66+ years	91 (39)	60 (36)	ns
Disease duration			
0-3 years		67 /30%	
4-9 years		111 /49%	
10+ years		47 /21%	
Gluten-free diet adherence			
Fully adherent		160 /70%	
Partially adherent		56 /25%	
Non-adherent		9 /5%	

ns = p >0.05

A high level of GFD adherence was reported: Full Adherence 65%, Partial Adherence 31%, None Adherence 4%. Eighty % of CD patients perceived adhering to the GFD as difficult: Impossible 5%, Mostly difficult 14%, Sometimes difficult 61%, No difficulty 20%. Lifestyle situations presenting difficulty when following a GFD were: 'eating out': 198/225 (88%); 'travelling': 164/225 (72%); 'socialising': 159/225 (71%); 'at home': 26/225 (11%); 'at work': 61/225 (27%) and, 'personal relationships': 29/225 (13%).

Comparison of control subjects versus fully GFD adherent patients versus partial/none adherent patients revealed the following results: (1) QoL: SF-36 PCS: 53.40 versus 47.34 versus 44.90 (P>0.05); SF-36 MCS: 50.77 versus 47.43 versus 43.08 (P >0.05) (Fig. 1); (2) Psychological wellbeing: HADS-A: 5.3 versus 7.0 versus 7.0 (P>0.05); HADS-D: 5.5 versus 6.0 versus 8.0 (P>0.05) (Fig. 2).

Comparison based on perceived degree of difficulty following a GFD in CD patients - No difficulty, Mostly difficult, Sometimes difficult, Impossible – revealed the following results: (1) QoL: SF-36 PCS: 49.07, 47.38, 39.48 and 35.50 (P >0.05); SF-36 MCS: 52.39, 44.64, 38.72 and 31.47 (P <0.0001) (Fig. 3); (2) Psychological wellbeing: HADS-A: 4.0, 7.0, 9.0 and 7.0 (P <0.0001); HADS-D: 5.0, 7.0, 11.0 and 8.0 (P <0.0001) (Fig. 4).

Based on socio-demographic/ACORN categories, Wealthy Achievers were three times more likely to be fully GFD adherent than their less affluent counterparts: Odds Ratio 0.33, 95% confidence interval 0.15-0.75 (P=0.0077); 28% of fully adherent patients held a university qualification versus 16% of partial/none adherent patients (P=0.064); 25% of fully adherent versus 24% of partial/none adherent patients were male (P >0.05); 72% of fully adherent versus 71% of partial/none adherent patients were married (P >0.05); 4% of fully adherent versus 12% of partial/none adherent patients were under 35 years of age (P=0.085).

Twenty-six % of fully adherent versus 31% of partial/none adherent patients had a disease duration of three years or less (P >0.05); 13% of fully adherent versus and 21% of partial/none adherent patients had a screen-detected method of presentation (P>0.05).

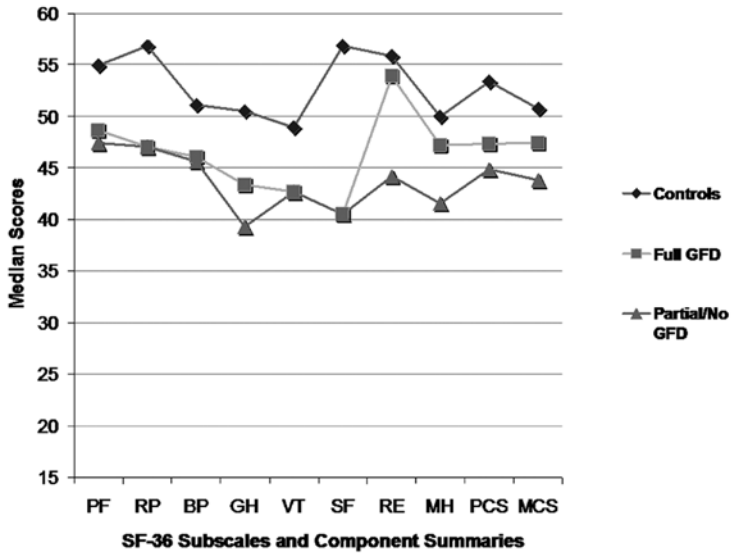

Fig 1. Quality of life (SF-36 scores) based on gluten-free diet (GFD) adherence level.

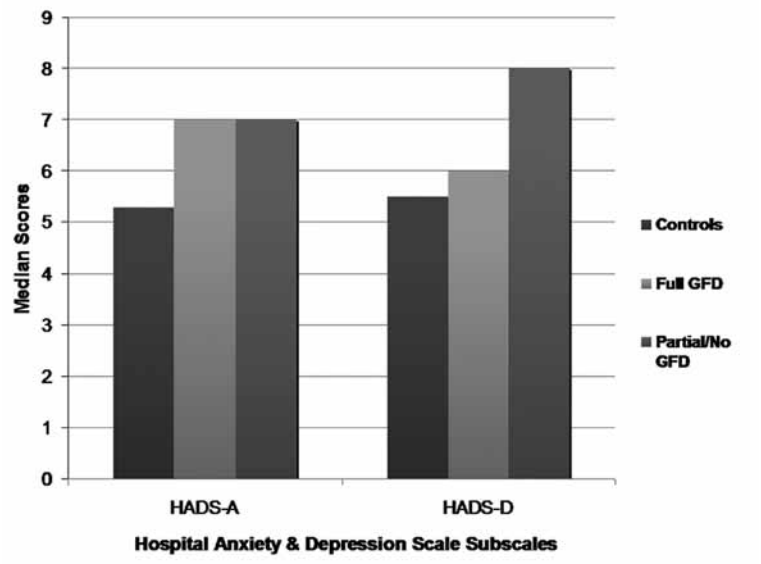

Fig 2. Likelihood of anxiety and depression (HADS scores) based on gluten-free diet (GFD) adherence level.

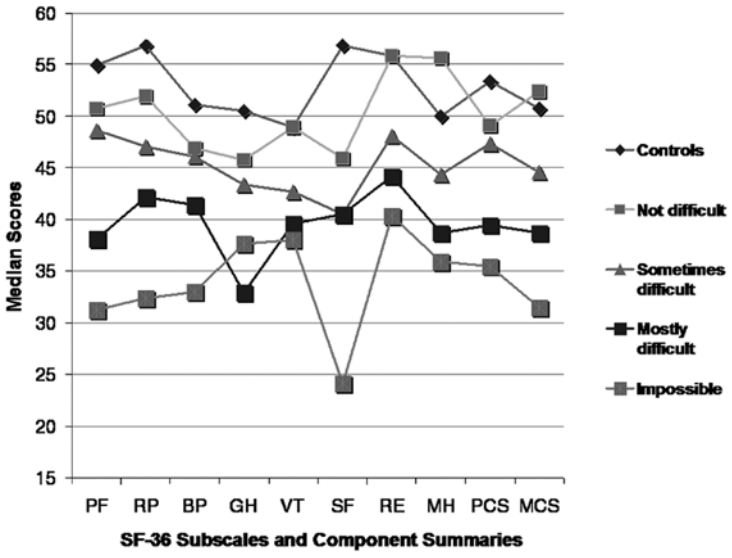

Fig 3. Quality of life (SF-36 scores) based on perceived degree of difficulty following a gluten-free diet (GFD).

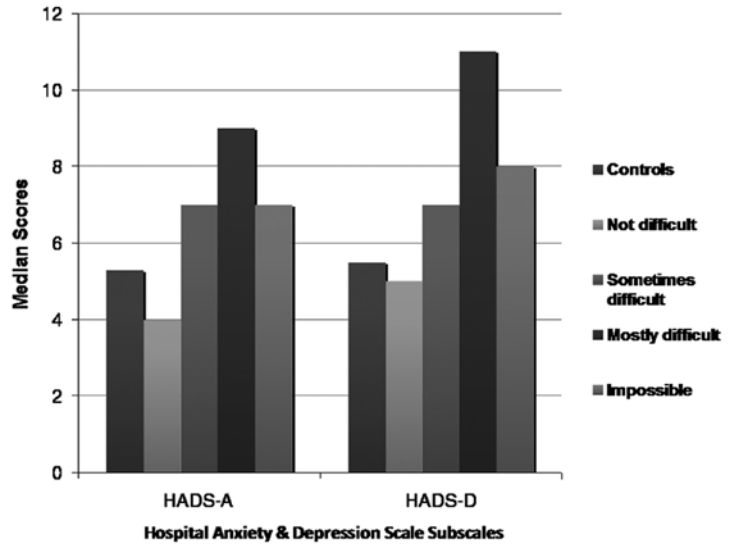

Fig 4. Likelihood of anxiety and depression (HADS scores) based on perceived degree of difficulty following a gluten-free diet (GFD).

Discussion

Coeliac disease patients have a reduced QoL and increased likelihood of anxiety and depression in comparison to age and sex-matched controls. When comparing CD patients who report full GFD adherence to those with partial or no adherence negligible differences in QoL and psychological wellbeing are found. However, on closer inspection marked differences are observed when CD patients are stratified based on their perceived degree of difficulty adhering to a GFD. This second finding would have been overlooked had we undertaken a traditional 'adherent versus non-adherent' comparison; as would the significant reduction in QoL and increased psychological distress experienced in our sample as a result.

Comparing our findings to those of previous investigators is, as discussed in our opening remarks, difficult due to the discrepancies between previous investigators' research methodologies. However, our findings that Coeliac patients have a reduced QoL in comparison to controls is consistent with UK [8] and Italian [10] studies previously mentioned.

Hallert et al [14] surveyed 89 CD patients ten years from diagnosis reporting reduced SF-36 scores in comparison to controls. The authors conclude that Vitality and General Health domains are particularly reduced with a mean score of 68.30 and 62.80, respectively. In all subscales we report much lower SF-36 scores than previous investigators: fully GFD adherent CD patients report Vitality scores of 43.0 (as do non-adherent patients) compared to their 68.30; a figure which is also much higher than our CD patients who report the greatest difficulty in adherence with Vitality scores of 37.0. Our GFD adherent CD patients report General Health scores of 43.0 in comparison to our non-adherent patients who score 39.0. Again these figures are lower than of the previous investigators 62.80. Perceiving the GFD as mostly difficult is associated with a General Health score of 32.0; a reduction of almost half in comparison to the 'significant reduction' reported by the previous investigators.

The mean disease duration in our sample is eight years in comparison to ten years in the sample described by the previous investigators. However, our patients have a disease

duration ranging from six months to fifty-years. This increase in disease duration may account for the reduced SF-36 we report in comparison to the previous, however, we have failed to report a meaningful association between increasing disease duration and QoL in our patients.

That a more affluent background, as rated by ACORN, is associated with greater GFD adherence is not surprising given that gluten-free food is often more expensive than 'regular' food products [6]. Furthermore, (ACORN) affluent patients are also more likely to own a car and have internet access at home and may be able to successfully overcome both the patchy availability of gluten-free foods in shops and supermarkets and the availability of gluten-free foods on restaurant menus [15].

The second patient characteristic associated with greater GFD adherence was a university education. Intelligence may be associated with better problem-solving skills and planning abilities, which allow the patient to overcome obstacles encountered following a GFD. However, this theory would need to be tested using instruments that accurately measure intelligence, such as IQ scores. We suggest that our results reflect that a university education confers social mobility, access to the professions and therefore a potentially greater capacity for wealth [16], thus permitting the advantages associated with the affluent standing of Wealthy achievers discussed in the previous section.

The clinical implications of our study focus on which member of the multi-disciplinary team is best placed to safeguard the Coeliac individual's QoL in the long term and with the greatest potential for benefit. We contend this falls within the domain of the dietician and not the gastroenterologist in whom we believe is more appropriately placed to diagnose and address the medical complications of CD; not how to successfully and satisfactorily engage in gluten-free living.

This study benefits from the use of valid and reliable measures of QoL and psychological wellbeing. Our use of ACORN categories as a means of stratifying patients based on socio-demographic background is, nonetheless, a novel approach in this context. Our broad inclusion criteria were intended to eliminate recruitment bias; however, as a postal survey we concede our findings are based solely on those individuals that chose to participate. Further research is required to validate our results.

Conclusion

Our current understanding of QoL in CD hinges upon GFD adherence level - an outcome measure, which we have demonstrated fails to reveal the true extent of how gluten-free living negatively impacts on QoL. We advocate a more comprehensive approach to which outcome measure(s) are employed by future researchers. Clinically, our findings reflect that whilst the majority of CD patients adhere to a GFD, the vast majority encounter difficulty doing so and as a consequence, patient QoL may be improved with greater dietary support and education.

Conflicts of interest

Nothing to declare.

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