

## CLINICAL NUTRITION

# Living with coeliac disease: survey results from the USA

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### Abstract

**Background:** The only treatment for coeliac disease is lifelong adherence to a rigorous gluten-free diet. The present study aimed to evaluate the influence of coeliac disease on the social aspects of daily life of individuals in the USA.

**Methods:** The present study used a self-administered survey including the standard Quality of Life questionnaire (12-item short-form) with validated disease-specific questions. SAS statistical software 2010 (SAS Institute, Cary, NC, USA) was used to calculate the mean (SD).

**Results:** Individuals with coeliac disease overall had a low positive health perception. Validated diet and disease-specific questions revealed a significant negative impact on quality of life in social settings. Specifically, the areas of travel, dining out and family life are most affected. The negative impact of diet significantly decreased over time, although it did not resolve for the domains of dining out of the home and travel. Those diagnosed in childhood and maintained on the diet had less of an impact on the quality of life as an adult.

**Conclusions:** Individuals with coeliac disease in the USA have a diminished quality of life, especially in the social aspects of life.

## Introduction

Coeliac disease is a genetically determined autoimmune disorder triggered by the inclusion of gluten in the diet (Dicke *et al.*, 1953; Green & Cellier, 2007). The clinical presentation may vary from asymptomatic to severe malabsorption (Casellas *et al.*, 2008). Coeliac disease was once considered to be a rare childhood disorder but it is now recognised to affect approximately 1% of the population (Green & Cellier, 2007). The only treatment for coeliac disease is lifelong adherence to a gluten-free diet. The strict nature of the diet has implications on an individual's quality of life (QoL), especially when considering the importance of dietary compliance and the rigidity of the dietary pattern (Cranney *et al.*, 2007; Black & Orfila, 2011). Indeed, in one study (Lee *et al.*, 2003), endoscopic biopsies demonstrated the presence of persistent villous atrophy and chronic inflammation despite a reported adherence to the gluten-free diet, suggesting that strict gluten avoidance is extremely difficult.

Quality of life is described as an all-encompassing perception of health and well-being, influenced by and impacting on all aspects of our lives. The domains of QoL include the social, religious, emotional, economic and physical well-being of an individual (Spilker, 1996), and QoL is influenced by and has effects upon the physical health and perception of wellness. Indeed, it should also be recognised that eating encompasses more than just meeting the physiological need for nutrients. It is interwoven into the fabric of our lives, culture, and social and emotional needs.

Although there have been several studies addressing the QoL among Europeans with coeliac disease, (Hallert *et al.*, 2002; Mustalahti *et al.*, 2002; Ciacci *et al.*, 2003; Casellas *et al.*, 2008; Sverker *et al.*, 2009) indicating that QoL is negatively impacted in individuals with coeliac disease, those with symptoms and women are most adversely affected (Casellas *et al.*, 2008). There have been limited studies from the USA where coeliac disease is considered to be underdiagnosed (Green *et al.*, 2001). One study from Canada (Cranney *et al.*, 2007) indicated

a significant negative impact on QoL in individuals with coeliac disease. The economic burden of the gluten-free diet has been reported previously (Lee *et al.*, 2007). The present study aimed to investigate the impact of both coeliac disease and the gluten-free diet on the social domain of QoL.

## Materials and methods

The self-administered surveys use the standard Quality of Life questionnaire (12-item short-form, SF-12), with additional questions from a coeliac-specific QoL pilot study (19 questions). The coeliac diet and disease-specific questions were used previously in a pilot study (Lee & Newman, 2003) and are included in a validated disease-specific QoL tool (Dorn *et al.*, 2010b). The SF-12 is a validated QoL instrument, which has been used to assess the status of individuals with coeliac disease in numerous studies (Hallert *et al.*, 1998, 2003; Mustalahti *et al.*, 2002; Johnston *et al.*, 2004; Casellas *et al.*, 2008). The coeliac diet and disease-specific questions asked about areas of dietary compliance, the impact of dietary compliance on QoL issues, such as travel, family life, health perception, social activities and dining out. The controls were invited to complete only the SF-12. The responses to the SF-12 were converted to ranked values, with the most negative responses assigned the lowest score (= 1) and more positive responses given progressively higher valued scores.

Introductory letters by post and e-mail were sent to the leaders of 40 support groups listed on a coeliac specific website, requesting their participation in the QoL study. Two thousand surveys were distributed via standard mail to the 30 coeliac support groups who responded to the inquiry. The coeliac support groups were representative of 17 states and included both urban and rural areas throughout the USA.

Inclusion criteria included age (>19 years), reported biopsy-proven coeliac disease, and adherence to a gluten-free diet. Questionnaires were collected from other household members as controls.

The Columbia University Institutional Review board approved both the study and a consent form, which was included with each survey. All responses were anonymous. SAS statistical software 2010 (SAS Institute, Cary, NC, USA) at the Irving Center for Research at Columbia University was used to analyse results.

## Results

Surveys from 1743 individuals with reported biopsy-proven coeliac disease were returned (87% response rate). Those respondents who did not meet the inclusion criteria of age, reported biopsy-proven coeliac disease, or did not

complete the survey were excluded from the study. The study population was predominately female, as reflects the prevalence of coeliac disease in the general population. The majority of the population (39%) was diagnosed 2–5 years before the survey. The length of time since diagnosis was in the range 0–1 year (20%) to over 20 years (49%). The length of time on a gluten-free diet was in the range 0–1 year (2%) to over 20 years (10%) (Table 1).

In the overall rating of QoL, there was no statistical difference between the individuals with coeliac disease and the control group. However, there were statistical differences between the two groups when asked about the specific areas of health or health perception. Only 85% of the individuals with coeliac disease, compared to 94% of the comparison group ( $P < 0.0001$ ), had a positive health perception (i.e. perception of one's health status).

The responses to the diet and disease-specific questions revealed the negative impact of having the disease, specifically in the social domain of QoL, with mean (SD) scores of 1.32 (1.04) for those with coeliac versus 1.78 (0.72) for the control group ( $P < 0.001$ ). Coeliac individuals were also significantly impacted in the areas of social activities

**Table 1** Population demographics

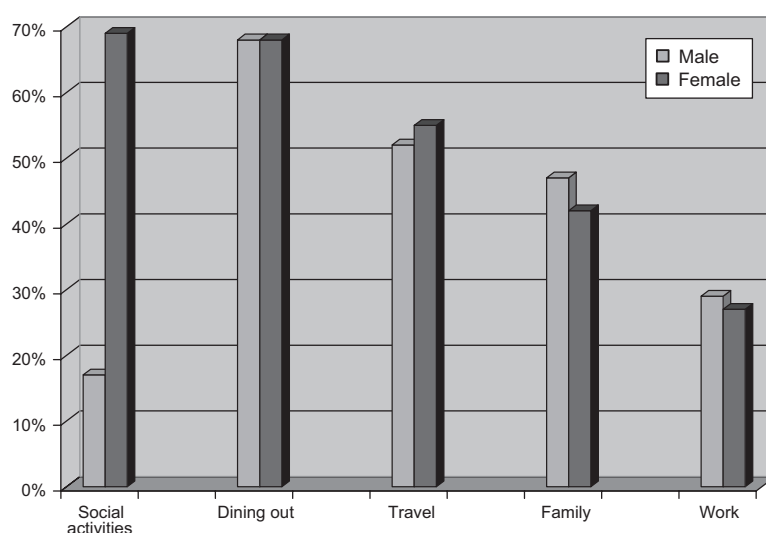
	Study population ( <i>n</i> = 1743)	Control population ( <i>n</i> = 1179)
Gender		
Male	23%	61%
Female	77%	39%
Age (years)		
18–45	26%	30%
46–65	44%	43%
Over 65	30%	28%
Education level		
Grammar school	1%	1%
High school	28%	26%
College	44%	44%
Advanced	27%	29%
Diagnosed in childhood	13%	
Symptoms	91%	
Length of time (years) since diagnosis		
0–1	20%	
2–5	39%	
6–10	18%	
11–15	9%	
16–20	4%	
Over 20	9%	
State regions	Number of states	
New England	4	
Middle Atlantic	3	
South	1	
Midwest	1	
Southwest	3	
West	5	

with family, friends or groups as compared to the control group, with a mean (SD) of 2.71 (0.52) for those with coeliac versus 2.79 (0.46) for control individuals ( $P < 0.001$ ). Additionally, 45% of the coeliac respondents reported that their physical health affected interaction with family, friends or social groups. There was no statistical significance in the difference between those with coeliac and the control group for age or the presence of other disease.

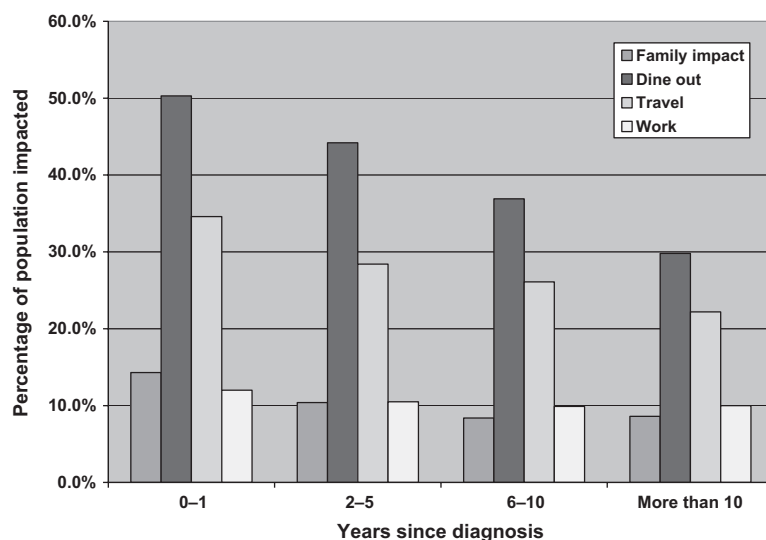
Although there was an overall negative effect from the gluten-free diet on the social domain, social activities were the only area where gender differences were apparent (Fig. 1). In the area of social activities, females were more negatively impacted (68%) compared to males (17%).

There is a persistent negative effect of the gluten-free diet on the social domain of QoL (Fig. 2). Dining out was the most negatively impacted area for each of the different time periods measured ( $P < 0.001$ ). Of note, 25% of the females and 28% of the males diagnosed in the 2–5 years time category chose not to dine out at all.

Travel was the next area that was most affected, where 10% reported an impact on family or work life. Of note, there was a progressive decline in the impact on dining out and travel with increasing years after diagnosis. Using the mean age in each sub group as the independent variable, the decline in percentage of population was  $-1.71\%$  per year for dining out ( $r^2 = 0.99$ ,  $P < 0.001$ ) and  $-0.95\%$  per year for travel ( $r^2 = 0.89$ ,  $P < 0.001$ ).



**Figure 1** Negative impact of a gluten-free diet on specific lifestyle areas by gender.



**Figure 2** Negative impact of a gluten-free diet on specific lifestyle areas over time.

Some 13.4% were diagnosed with coeliac disease in childhood (<12 years) and had remained on the diet into adulthood ( $n = 221$ ; 13% of the males and 14% of females of the study population). Overall QoL (multidimensional perception of one's overall life) was rated as positive in 84% of individuals diagnosed in childhood compared to only 49.7% of women and 50.3% of men diagnosed later in life. In addition, those individuals diagnosed in childhood had little or no negative impact from a gluten-free diet on QoL compared to those diagnosed as adults within 2–5 years of taking the survey.

Compliance with the gluten-free diet had a negative impact on QoL on both genders with coeliac disease. Interestingly, both males and females reported a high rate of compliance (98% each for males and females). However, when asked whether they intentionally went off the diet, a surprising number admitted to dietary indiscretion. Males reported intentionally going off the diet at social activities 81% of time, 82% at restaurants and 58% with friends (Fig. 3). Females reported a slightly higher degree of intentional noncompliance 88% at social activities, 88% in restaurants and 67% with friends. These numbers represent a high degree of noncompliance with a medically necessary diet regime. When queried as to the reason for noncompliance, 73% reported that the diet was too restrictive ( $P = 0.01$ ). Other reasons reported for noncompliance included finding the diet uncomfortable in social settings (69%), difficult to follow (68%), tasteless (45%) and too expensive (33%).

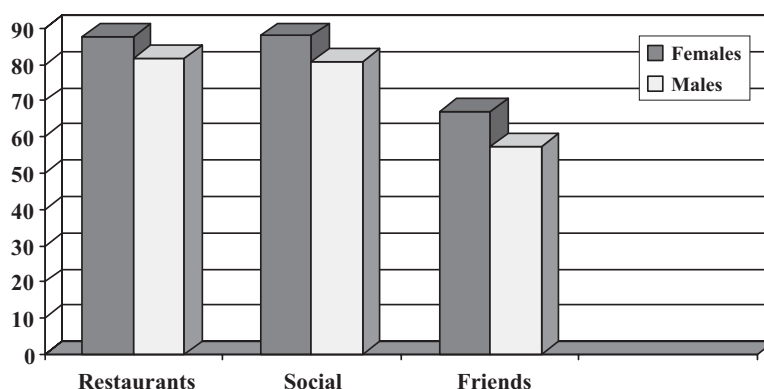
## Discussion

Overall, the results reported in the present study are similar to those of other studies reporting an improvement in perceived QoL since diagnosis and commencement of the gluten-free diet (Hallert *et al.*, 1998; Green *et al.*, 2001; Lee & Newman, 2003; Johnston *et al.*, 2004; Cranney

*et al.*, 2007; Casellas *et al.*, 2008; Black & Orfila, 2011). The negative impact on QoL was most striking when the areas of social activities, length of time on the diet and compliance were queried. These findings are similar to the results of the Canadian Health Survey (Cranney *et al.*, 2007), as well as the study by Black & Orfila (2011).

Compared to the overall QoL, the negative impact of diet and disease was statistically significant in the social domain of QoL (Fig. 1). A significant negative impact associated with dietary adherence was found in social settings such as dining out, travel and family life (Fig. 1). These findings have also been documented in the study by Black & Orfila (2011). The diet/disease-specific questions revealed a significant negative impact on the areas of social activities with family, friends or groups, although there was less impact on the ability to work (Fig. 1). In the study by Black & Orfila (2011), reports of anxiety and depression were linked to feelings of exclusion from social events and leisure activities. The overall implication of these findings is the recognition of the difficulty of dietary compliance, particularly in social settings because the only treatment for this disorder is a strict life-long gluten-free diet. Compared to the less rigid application of a gluten-free diet for weight loss and generalised improved health, there is a decreased awareness of coeliac disease and the medical necessity of lifelong, or strict, dietary adherence in the USA. Unlike the study reported by Casellas *et al.* (2008) in which the QoL was more negatively impacted in female participants, the present study found that the genders equally shared the burden of diet and disease.

The length of time since diagnosis and the difference between those in whom a diagnosis had been made in childhood compared to diagnosis as an adult had not been studied previously. Both of these factors apparently affect an individual's QoL. The length of time since diagnosis also had a significant impact on QoL. We found



**Figure 3** Location and frequency of intentional ingestion of gluten by gender.

that the negative impact of diet significantly decreased over time, although it did not resolve for the domains of dining out of the home and travel (Fig. 2). Further research is warranted to determine whether the decreasing impact over time is a result of familiarity with the diet regime with increasing time on the diet, the manner of presentation or other variables. In the study by Casellas *et al.* (2008), adults usually present with fewer symptoms or no symptoms at all, which may negatively impact the perceived need for compliance with the gluten-free dietary pattern. The recognition that those diagnosed in childhood and maintained on the diet had less of an impact on the QoL (Fig. 2) is a potentially important observation because it suggests the need for early diagnosis and treatment. It is also important for parents, who may be concerned that difficulties with the diet will socially impair their child who has been diagnosed with coeliac disease (Hallert *et al.*, 2003). Further studies will be needed aiming to determine the cause of the positive effects of early detection and long-term dietary adherence and to determine the impact of dietary adherence during childhood (Kurppa *et al.*, 2011).

Of particular interest was the insight into the perceived compliance with the gluten-free diet. The perceived high degree of compliance (98%) contrasts sharply with the equally high degree of acknowledged intentional ingestion of gluten in social situations (Fig. 3). Indeed, the high degree of noncompliance, as found in the present study, may also account for the persistent chronic inflammation and villous atrophy noted in the previous study of patients on the diet long-term (Lee *et al.*, 2003) and reflects a 'disconnect' between degree of dietary adherence or compliance and deliberate non-adherence in the social setting. This suggests that there may be an important role for nondietary pharmaceutical therapies in the management of coeliac disease.

## Conclusions

Adherence to a lifelong dietary regime, such as a gluten-free diet, has the potential to affect many of the domains of QoL: economic, social and physiological. An individual's diet encompasses more than just the meeting an individual's physiological need for nutrients. It is often interwoven into the fabric of our lives, including culture, social and emotional needs. QoL issues are probably one of the major causes of noncompliance among individuals with coeliac disease (Dorn *et al.*, 2010a). Individuals are faced with many roadblocks when following a gluten-free diet. These include inadequate food labelling, expense of gluten-free products where unavailable on prescription (Lee *et al.*, 2007), ubiquitous use of wheat as an additive in many foods, which can therefore be present as a con-

taminant, lack of knowledge of ingredients in restaurants, and lack of public awareness and acceptance of the concept of gluten intolerance by the public and health care providers.

In the USA, adhering to the gluten-free diet is associated with a negative impact on QoL, especially in the social domain. The present study highlights two important factors. First, the need for further research to pinpoint the areas affected by the burden of a gluten-free diet. Second, there is a need for clinicians to be aware of the negative impact on QoL in individuals with coeliac disease. Many questions remain in terms of the impact on children, adolescents and those diagnosed with asymptomatic or minimally symptomatic coeliac disease. Further studies need to be conducted with age- and gender-matched control groups. A cross-cultural QoL disease-specific comparison in areas where gluten-free products are available on prescription may provide further insight to the origin of the negative impact found in this population. Clinicians should provide information, tools and support to their patients to diminish the burden of diet and disease. In addition, patients need to be educated on the physiological impact of intentional dietary indiscretions. Additionally, resources such as contacts or links to support groups, social networking sites and web sites, as well as travel and dining groups, need to be provided to the newly diagnosed.

## Strengths and limitations

The strengths of the present study include the large number of respondents, the representation from diverse areas of the USA, and the use of diet and disease-specific questions.

The limitations of the present study include a study population bias because the respondents were members of support groups, which may not be representative of the coeliac population as a whole. Members of support groups may be less negatively impacted because the support group would offer a sense of community and social support. In addition, the fact that the respondents were virtually all symptomatic before their diagnosis of coeliac disease may not be reflective of the coeliac population as a whole. The household comparison group also may not have been representative of a control group. The burden of cohabitation with someone with a chronic condition may have affected their responses, and the gender differences between the groups need to be considered as limitations.

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### Conflict of interest, source of funding and authorship

The authors declare that they have no conflict of interests. Study Support: This study was conducted without any outside financial support, grants or donations. ARL was study guarantor, primary planner and conductor, and also drafted the manuscript. PHRG planned, drafted and edited the manuscript. DN conducted data analysis and input. BD and EJC performed statistical analysis. All authors critically reviewed the manuscript and approved the final version submitted for publication.

### References

- Black, J.L. & Orfila, C. (2011) Impact of celiac disease on dietary habits and quality of life. *J. Hum. Nutr. Diet.* **24**, 582–587.
- Casellas, F., Rodrigo, L., Vivarcos, J.L., Riestra, S., Pantiga, C., Baudet, J.S., Junquera, F., Divi, V.P., Abadia, C., Papo, M., Gelabert, J. & Malagelada, J.R. (2008) Factors that impact health-related quality of life in adults with celiac disease: a multicenter study. *World J. Gastroenterol.* **14**, 46–52.
- Ciacci, C., D'Agate, C., DeRosa, A., Francese, C., Errichiello, S. & Gasperi, V. (2003) Self rated quality of life in celiac disease. *Dig. Dis. Sci.* **48**, 2216–2220.
- Cranney, A., Zarkadas, M., Graham, I.D., Butzner, J.D., Rashid, M., Warren, R., Molly, M., Case, S., Burrows, V. & Switzer, C. (2007) The Canadian celiac health survey. *Dig. Dis. Sci.* **52**, 1087–1095.
- Dicke, W.K., Weijers, H.A. & van de Kamer, J.H. (1953) Coeliac disease. II The presence in wheat of a factor having a deleterious effect in cases of coeliac disease. *Ada Paediatr.* **42**, 34–42.
- Dorn, S.D., Hernandez, L., Minaya, M.T., Morris, C.B., Hu, Y., Leserman, J., Lewis, S., Lee, A., Bangdiwala, S.I., Green, P.H. & Drossman, D.A. (2010a) The development and validation of a new coeliac disease quality of life survey (CD-QOL). *Aliment. Pharmacol. Ther.* **31**, 666–675.
- Dorn, S.D., Hernandez, L., Minaya, M.T., Morris, C.B., Hu, Y., Lewis, S., Leserman, J., Bangdiwala, S.I., Green, P.H. & Drossman, D.A. (2010b) Psychosocial factors are more important than disease activity in determining gastrointestinal symptoms and health status in adults at a celiac disease referral center. *Dig. Dis. Sci.* **55**, 3154–3163.
- Green, P.H. & Cellier, C. (2007) Celiac disease. *N. Engl. J. Med.* **357**, 1731–1743.
- Green, P.H.R., Stavropoulos, S., Pangagi, S., Goldstein, S., McMahon, D.J., Absan, H. & Neugut, A.I. (2001) Characteristics of adult celiac disease in the USA: results of a national survey. *Am. J. Gastroenterol.* **96**, 126–131.
- Hallert, C., Granno, C., Hulten, S., Midhagen, G., Strom, M., Svensson, H., Valdimarsson, T. & Wickstrom, T. (1998) Quality of life of adult celiac patients treated for ten years. *Scand. J. Gastroenterol.* **33**, 933–938.
- Hallert, C., Granno, C., Hulten, S., Midhagen, G., Strom, M., Svensson, H. & Valdimarsson, T. (2002) Living with celiac disease: controlled study of the burden of illness. *Scand. J. Gastroenterol.* **37**, 39–42.
- Hallert, C., Sandlund, O. & Broqvist, M. (2003) Perceptions of health-related quality of life of men and women living with celiac disease. *Scand. J. Caring Sci.* **17**, 301–307.
- Johnston, S., Rodgers, C. & Watson, R.G.P. (2004) Quality of life in screen detected and typical celiac disease and the effect of excluding dietary gluten. *Eur. J. Gastroenterol. Hepatol.* **16**, 1281–1286.
- Kurppa, K., Collin, P., Maki, M. & Kaukinen, K. (2011) Celiac disease and health-related quality of life. *Expert Rev. Gastroenterol. Hepatol.* **5**, 83–90.
- Lee, A.R. & Newman, J. (2003) Celiac diet: impacts on quality of life. *J. Am. Diet. Assoc.* **103**, 1533–1535.
- Lee, S.K., Lo, W., Memeo, L., Rotterdam, H. & Green, P.H. (2003) Duodenal histology in patients with celiac disease after treatment with a gluten-free diet. *Gastroenterol.* **57**, 187–191.
- Lee, A.R., Ng, D.L., Zivin, J. & Green, P.H.R. (2007) Economic burden of a gluten-free diet. *J. Hum. Nutr. Diet.* **20**, 423–430.
- Mustalahti, K., Lohiniemi, S., Collin, P., Voutilainen, N., Laippala, P. & Maki, M. (2002) Gluten-free diet and quality of life in patients with screen-detected celiac disease. *Eff. Clin. Pract.* **5**, 105–113.
- Spilker, B. (1996) *Quality of Life and Pharmacoeconomics in Clinical Trials*, 2nd edn. Philadelphia, PA: Lippincott-Raven Publishers.
- Sverker, A., Ostlund, G., Hallert, C. & Hensing, G. (2009) 'I lose all these hours...' – exploring gender and consequences of dilemmas experienced in everyday life with coeliac disease. *Scand. J. Caring Sci.* **23**, 342–352.