Food knowledge and psychological state predicts adherence to a gluten-free diet in a survey of 5310 Australians and New Zealanders with coeliac disease

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SUMMARY

Background: A gluten-free diet treats coeliac disease, but its efficacy dependents on strict adherence. A variety of patient factors may influence adherence but have not been well described at a population level.

Aim: To comprehensively assess the patient factors that influence gluten-free diet adherence in patients with coeliac disease.

Methods: Patients with coeliac disease completed an online survey comprising the validated Celiac Dietary Adherence Test in addition to data on demographics, details of diagnosis and management and assessment of diet knowledge, quality of life and psychological distress. Survey data were analysed for predictors of adherence and quality of life.

Results: Of 7393 responses, 5310 completed the Celiac Dietary Adherence Test and 3230 (61%) were adherent to a gluten-free diet. Multivariate regression showed older age, being male, symptoms after gluten ingestion, better food knowledge and lower risk of psychological distress were independent predictors of adherence (each $p \leq 0.008$). Additionally, dietary adherence was associated with better quality of life ($p < 0.001$; multiple regression). Respondants who considered themselves to have poor food knowledge were more likely to incorrectly identify gluten-free foods, but could still recognise gluten-containing foods, suggesting that poor knowledge may lead to over-restriction of diet.

Conclusions: Poor knowledge of a gluten-free diet and psychological wellbeing were independent modifiable risk factors for inadequate adherence to a gluten-free diet in patients with coeliac disease. Involvement of both a dietitian and mental health care professional, in the presence of psychological distress, is likely to be necessary to improve adherence and health outcomes.

Keywords: Coeliac disease, General practice, Compliance/adherence, Small intestine

INTRODUCTION

Coeliac disease is a chronic autoimmune condition characterised by small intestinal villous atrophy and often presenting with clinical symptoms[1]. The only current treatment coeliac disease is a strict gluten-free diet to achieve clinical and histological remission, thereby reducing risk of associated nutritional deficiencies, infertility, osteoporosis and gastrointestinal malignancies[2, 3]. The estimated prevalence of coeliac disease is growing, particularly in Western countries[4, 5], with Australia having one of the highest estimated prevalence of approximately 1.5%[6]. While a gluten-free diet is considered a safe and largely efficacious treatment, it is costly[7] and can be socially isolating[8], which have been shown to be barriers to dietary adherence[9-11]. Furthermore, due to the nature of a dietary treatment, there is arguably a bigger burden of responsibility on the patient compared to many medication-based treatments[12]. Patient factors that predict good adherence are therefore very relevant to achieving optimal treatment.

Data on dietary adherence of a gluten-free diet in a coeliac disease population are variable, with rates ranging between 42-91%, depending on definition and method of assessment[13]. Studies from North America and Europe have associated dietary adherence with higher levels of education, younger age at diagnosis[11, 13, 14], membership of coeliac disease advocacy groups[10], quality of life and mental disorders[15, 16] but sample sizes have been small and possibly not representative at a population level. However, examination of clinically relevant factors that may be targeted in patient management to improve adherence, such as food knowledge, quality of life and psychological distress, have remained unexplored in Australia and New Zealand, where there is high prevalence of coeliac disease and stricter definition of a gluten-free diet compared to other countries. The aim of this study was to comprehensively assess the patient factors that influence gluten-free diet adherence in

patients with coeliac disease in Australia and New Zealand through a large cross-sectional survey. A secondary aim was to assess predictors of quality of life, including dietary adherence. It is hypothesised that there will be several factors associated with adherence including knowledge and psychological parameters.

METHODS

Survey description

An internet-based survey (SurveyMonkey®; San Mateo, California, USA) was used to gather data. All participants accessed the survey via a web-link. The survey was advertised via Coeliac Australia and Coeliac New Zealand membership communications, state-based Gluten Free Expos open to the public, Facebook pages of coeliac disease and word-of-mouth. The survey was open for completion for approximately one month. To capture adults and adolescents with established coeliac disease, the advertisement specified that patients diagnosed with coeliac disease for at least six months and aged ≥ 13 years were to complete the survey. On entering the survey website, an introductory paragraph described the target population and the purpose of the survey, which was to identify predictors of adherence to a gluten-free diet. It specified that only the person with coeliac disease was to complete the survey and strict adherence to the diet was not essential for eligibility. It was confirmed that participation was voluntary and any provided personal identifying information was optional and kept confidential.

The survey comprised of 44 questions and took approximately 15 minutes to complete. An additional 37 questions were included, to assess psychological factors impacting adherence[17]. Data from this model are described elsewhere[18]. The first question was used to obtain consent. If the participant did not consent to take part in the survey, they were directed to the survey completion page. If consent was obtained, participants were then

asked an inclusion criterion question for confirmation of coeliac disease. Participants were directed to the survey completion page if they answered 'No' or 'Unsure' to the question 'Do you have coeliac disease?'.

The survey contained the seven-question Celiac Dietary Adherence Test[19], a tool validated for evaluation of gluten-free diet adherence in a coeliac disease population. Each item is answered using a five-point response scale, where total score of greater than 12 designates non-adherence to a gluten-free diet (range 7-35). The rest of the survey was designed to capture information related to treatment adherence, including data on demographics, coeliac disease diagnosis and management, dietary restrictions (other than gluten), questions to assess knowledge of coeliac disease and a gluten-free diet and memberships to coeliac disease-related groups. The Coeliac Disease Quality of Life survey[20] was included, which is a validated measure of quality of life in the studied population. The Coeliac Disease Quality of Life survey uses a five-point response scale for 20 questions (scores ranging 20-100) and a higher score indicating a poorer quality of life. Lastly, the 10-item Kessler Psychological Distress Scale was also used to screen for anxiety and mood disorders[21, 22]. Scores for the Kessler Psychological Distress Scale range 10-50 and categorisation of levels of psychological distress were based on that previously used in Australian primary healthcare settings[23]; a score less than 20 specifies a person likely to be well, 20-24 likely to have a mild mental disorder, 25-29 moderate and scores 30 and over likely to have a severe mental disorder.

Survey development

Besides the validated questions of the Celiac Dietary Adherence Test, Coeliac Disease Quality of Life survey and Kessler Psychological Distress Scale, additional questions were

developed with input from a panel of clinicians from Australia and UK (gastroenterologists, dietitians and psychologists), then tested on lay people with coeliac disease undertaking other studies at WEHI and employees of Coeliac Australia and Coeliac New Zealand and their feedback considered. Most volunteers completed the survey within 15 minutes. Authors approved the final version of the survey.

The questions in the knowledge section were based upon consensus opinion of four dietitians with expertise in coeliac disease, which is considered the gold standard for assessing knowledge[24, 25]. The participants were asked i) three dichotomous 'true or false' questions related to coeliac disease, ii) to distinguish whether eight grains (e.g., corn, buckwheat, spelt) were gluten-free or gluten-containing, and iii) to identify whether nine ingredients (e.g., soybeans, yeast, barley malt extract) were gluten-free or gluten-containing, all according to the FSANZ code[26, 27]. From this latter knowledge of ingredients, a 'knowledge score', allocating one point to each correctly answered ingredient out of nine was generated. Additionally, participants rated their knowledge on how to adequately follow a gluten-free diet according to the categories 'excellent', 'good', 'fair', 'poor' and 'terrible'.

Statistical analyses

All descriptive data, including participants' demographics, were non-parametric according to D'Agostino's K-squared test and presented as median and interquartile range. Adherence to a gluten-free diet was based upon the validated Celiac Dietary Adherence Test score, which defines adequate adherence as a score of 7-12, and inadequate as a score of 13-35[24]. As degree of non-adherence has very little clinical importance, categorical definition of adherence was used as the outcome measure. Multivariate analysis of gender, age, ethnicity, level of education, household income, what led to diagnosis (i.e., symptoms, screening or

investigation of associated medical condition), symptoms after ingesting gluten, Kessler Psychological Distress Scale and knowledge score was performed by logistic regression. As another outcome variable, the same factors were also used in a multiple linear regression model to predict the continuous variable of Coeliac Disease Quality of Life survey score. Estimated adherence probability were averaged for groupings of age and the Kessler Psychological Distress Scale. Knowledge scores were further analysed by comparison to self-assessed rating of gluten-free knowledge and likelihood of over- versus under-restriction of gluten as defined by incorrect identification of gluten-free and gluten-containing ingredients. All statistical analyses were analysed with GraphPad Prism® and regression models were run in R® program. A p-value of ≤ 0.05 was considered statistically significant.

RESULTS

Survey response

Of 7393 respondents, 26 did not consent to participating in the survey and a further 183 (2%) did not have, or were unsure if they had, coeliac disease. These participants were immediately directed to the survey completion page. Together with 140 subjects who dropped out of the survey before completing these two eligibility questions, 7044 participants remained for analysis (Figure 1). The majority of the respondents were alerted to the survey via Coeliac Australia or Coeliac New Zealand (4297; 61%), 1921 (27%) through social media and the rest via other means.

Demographics

Demographics of the 7044 respondents are detailed in Supplement 1. Almost 80% of respondents were female, over 36 years of age, and from Australia (80%). Fourteen percent

were from New Zealand, which is a similar response rate to Australia per capita and the vast majority were Caucasian (91%).

Diagnosis and management of coeliac disease

Descriptions of diagnosis and management of the 7044 participants are detailed in Table 1. Most were diagnosed with coeliac disease via gastroscopy and small bowel biopsy (84%). A small proportion of people (2%) claimed to be diagnosed via the non-diagnostic methods of HLA genotyping and/or symptoms and the data from those respondents were included in the analysis (Table 1). Approximately half the participants (n = 3591) were investigated for coeliac disease due to symptoms; however, almost three-quarters of participants (n = 5195) reported symptoms after gluten exposure (Table 1). Upon diagnosis, more than one-third of people had not seen a dietitian for education of a gluten-free diet and, of these, many sought information from their state coeliac disease organisation (n = 1567; 22%), the internet (n = 1281; 18%) and from friends/family (n = 713; 10%); 58 people reported having received no information about treatment at all. When asked whether they follow a gluten-free diet, 1% (53) of participants responded 'no' and the main reasons for non-adherence were difficulty during travel (n = 22), general difficulty in following the diet (n = 21), expense (n = 19), lack of symptoms (n = 19) and enjoyment of gluten-containing foods (n = 17). As recommended by the national food standards[27], the majority of people do not eat oats as part of a gluten-free diet (86%) (Table 1). A large proportion of people (40%) were also restricting another food component, the most common restriction being lactose (n = 1124), 622 were following a low FODMAP diet, 461 were dairy free, and 303 were pescatarian, vegetarian or vegan.

Knowledge of coeliac disease and a gluten-free diet

A total of 6312 participants completed the knowledge questions. Most participants rated themselves as excellent (n = 4088; 65%), twice as many as good (n = 2006; 32%), followed by fair (n = 194; 3%). Only 21 and three participants rated themselves as having poor and terrible knowledge, respectively. The knowledge score, based on correct identification of nine ingredients as gluten-free or gluten-containing, was associated with self-assessment of knowledge (perfect score in self-rating categories from 'excellent', 'good', 'fair', 'poor' and 'terrible' were 46%, 28%, 17%, 5% and 0, respectively; $P < 0.001$; chi-square analysis). Correct identification of gluten-containing ingredients was similar amongst each self-ranked knowledge category; however, participants in a lower self-rating knowledge category were less likely to correctly identify gluten-free ingredients (Figure 2), indicating that someone with poorer knowledge was more likely to over- than under-restrict their diet. A better self-rated knowledge category was also associated with better understanding of coeliac disease (perfect score in descending order of self-rating categories 92%, 90%, 81%, 71%, 100%; $P < 0.001$). Similar results were seen regarding identification of gluten-free and gluten-containing grains. Many people incorrectly identified spelt as gluten-free (19%) and buckwheat as gluten-containing (11%). Membership of Coeliac Australia or Coeliac New Zealand was associated with better knowledge (membership 77%, 74%, 61%, 43%, 33%; $P < 0.001$).

Quality of life and psychological distress

Of the 5310 participants who completed the Coeliac Disease Quality of Life survey, median[interquartile range(IQR)] Coeliac Disease Quality of Life scores were 44[34-57]. The percentage of respondents who fit into the Kessler Psychological Distress Scale for being well,

having a mild, moderate and severe mental disorder were 72%, 14%, 7%, 7%, respectively. Most people were well (15[12-20]).

Predictors of adherence to a gluten-free diet

Of the 5310 respondents who completed the Celiac Dietary Adherence Test, 3230 (61%) were adherent to a gluten-free diet. Multivariate association coefficient estimates from a logistic regression model with adherence to a gluten-free diet are shown in Table 2. Independent predictors of adherence included older age, being male, adverse symptoms after gluten ingestion (severe symptoms Odds Ratio (OR) 1.58 compared to no symptoms), better knowledge scores in determining gluten-free on food labels (OR 1.19) and lower risk of psychological distress indicated by the Kessler Psychological Distress Scale (OR 1.18) (Table 2).

The estimated adherence probability increased with age and was poorest between the ages of 13 to 26 years and worse with increasing risk of mental disorder according to the Kessler Psychological Distress Scale (Figure 3).

Predictors of poorer quality of life

Independent predictors of a poorer quality of life indicated by the Coeliac Disease Quality of Life score are shown in Table 3. Age, severity of symptoms after gluten ingestion, psychological distress and adherence to a gluten-free diet were found to be significant predictors of quality of life (Table 3). Specifically, poorer quality of life was significantly associated with a younger age, possibly due to the impact of coeliac disease on the social lifestyle in younger people. Unsurprisingly, the more severe the symptoms, the greater the impact on quality of life (Table 3). The impact of severe symptoms on quality of life was

estimated to be nearly three times as large as that seen in those with moderate symptoms (coefficient estimate of 3.05 for severe symptom versus 1.17 for moderate symptoms; Table 3). Additionally, greater likelihood of psychological distress, as indicated by the Kessler psychological distress scale, was also found to be associated with lower quality of life (Table 3). Lastly, non-adherence to a gluten-free diet was estimated to have almost the same level of negative impact on quality of life as the presence of severe symptoms after gluten ingestion (Table 3).

DISCUSSION

Adherence to a gluten-free diet is crucial for adequate treatment of coeliac disease, but adherence rates vary greatly. Difficulties in determining rates and predictors of adherence may be due to small sample sizes of past studies. This survey-based study of over 7000 people with coeliac disease is the largest of its kind, both within Australasia, and worldwide. Of the 5310 survey respondents who provided adherence data, 61% had excellent or very good adherence to a gluten-free diet. It is important to acknowledge that there were a large proportion of respondents who were members of their coeliac disease advocacy organisations (68%). It is probable these respondents are more informed and health conscious, so the rate of adherence described may over-estimate what is seen in the general coeliac disease population, although 61% is comparable to other studies utilising the Celiac Dietary Adherence Test[28, 29].

Independent predictors of adherence were male gender, older age, more severe symptoms associated with gluten ingestion, better knowledge scores and lower psychological levels of distress. Factors such as adverse symptoms and food knowledge associating with better adherence are both predictable and consistent with previous research[25, 30]. An

interesting finding in this study was that people with self-perceived poorer knowledge in reading labels were more likely to incorrectly identify gluten-free foods but could still recognise gluten-containing foods, yet, were more likely to be non-adherent. A barrier to good adherence in some patients could be the perception that a gluten-free diet is more restrictive and harder than it actually is. These data suggest that referring non-adherent patients to a dietitian may be of value if their knowledge level in applying a gluten-free diet is poor. On the other hand, psychological distress was very common amongst people with coeliac disease who were non-adherent. In the presence of an underlying mental health problem, mental health assessment is appropriate and treatment may potentially support improved adherence, particularly if assessment of their knowledge skills[19, 25] is deemed adequate. The proportion of people with elevated psychopathology, indicated by Kessler Psychological Distress Scale, is comparable to other studies conducted in patients with coeliac disease[31]. While being male and older are unexpected factors associated with adherence to a gluten-free diet, these factors are non-modifiable and potentially, the older age may indicate a longer time since diagnosis. Screening studies indicate coeliac disease affects a higher proportion of females in Australia and New Zealand[32, 33] and this sex bias is particularly prominent in diagnosed members of the national patient groups, Coeliac Australia and Coeliac New Zealand (4F:1M; personal communication, Coeliac Australia and Coeliac NZ). Thus, this study sample appears quite representative of the sex distribution of people actually diagnosed with coeliac disease however an undetected sex bias could potentially affect results.

Quality of life was assessed as a separate outcome variable because literature has been conflicting in whether people with treated coeliac disease had better or worse quality of life than the general population[34, 35]. These past studies were conducted in different times and

countries, so perhaps the quality of life was more reflective of ease of application of treatment. Anecdotally, a gluten-free diet is becoming easier to apply in Australia in recent years, as indicated by increased variety and choice of gluten-free manufactured food products and improving availability in restaurants in metropolitan Australian cities[36]. The current findings indicate that good adherence to a gluten-free diet was associated with the presence of increasing symptom severity after gluten ingestion. It may be that application of a gluten-free diet is less onerous than in past times and the improved health outcomes, including symptoms, now outweigh the difficulties of the diet in a proportion of patients.

While not the main aim of this study, an added benefit of completing a survey of this considerable magnitude is that it allows acquisition of important data on diagnosis and management of Australians and New Zealanders with coeliac disease. These findings suggest that the method of diagnosis of coeliac disease is much better than expected[37, 38], with 84% being adequately diagnosed via gastroscopy and small bowel biopsy, the current gold standard of diagnosis[1]. Only 2% of survey respondents were inappropriately diagnosed by non-diagnostic methods and the data from those respondents were included in analysis. Again, this may be impacted by the high rates of respondents who are members of their state coeliac disease organisation. It is expected that more motivated people complete surveys, but even recent Australian survey data have showed that the majority of people who follow a gluten-free diet do not have adequate investigation of coeliac disease[37], although this was a different population studied. Perhaps more surprising information is that over one-third of people diagnosed with coeliac disease have never seen a dietitian and will rely on the internet, friends/family for their information of treatment. This may be an explanation for the general poor rates of food knowledge amongst the survey respondents and specifically the poor ability to identify gluten-free food (Figure 2). Indeed, the most common complaint

of survey respondents who did not follow a gluten-free diet was experiencing difficulty in following the diet in all or some environments, such as while travelling. These findings support consensus treatment guidelines that stress the importance of newly diagnosed patients having thorough education of a gluten-free diet, including advice on diet practicalities, preferably from a dietitian with expertise in coeliac disease[39, 40]. Additionally, as a large proportion of people are also restricting other food components, such as lactose and FODMAPs (16% and 9%, respectively), expert advice on how to minimise excessive restriction and ensure nutritional adequacy that is tailored to each individual patient's needs is indicated.

Cross-sectional survey evaluation of adherence to a gluten-free diet in Australian and New Zealander patients with coeliac disease showed that poor knowledge of applying a gluten-free diet and reduced psychological wellbeing were independent modifiable risk factors for inadequate adherence to a gluten-free diet. Dietitian involvement in patient management and involvement of a mental health care professional in the presence of psychological distress should improve adherence and health outcomes.

References:

1. Ludvigsson JF, Leffler DA, Bai JC, et al. The Oslo definitions for coeliac disease and related terms. Gut. 2013;62(1):43-52.

2. Kaukinen K, Peräaho M, Lindfors K, et al. Persistent small bowel mucosal villous atrophy without symptoms in coeliac disease. Aliment Pharmacol Ther. 2007;25(10):1237-45.

3. Lebwohl B, Granath F, Ekbom A, et al. Mucosal healing and risk for lymphoproliferative malignancy in celiac disease: a population-based cohort study. Ann Intern Med. 2013;159(3):169-75.

4. Lohi S, Mustalahti K, Kaukinen K, et al. Increasing prevalence of coeliac disease over time. Aliment Pharmacol Ther. 2007;26(9):1217-25.

5. Rubio-Tapia A, Kyle RA, Kaplan EL, et al. Increased prevalence and mortality in undiagnosed celiac disease. Gastroenterol. 2009;137(1):88-93.

6. Anderson RP, Henry MJ, Taylor R, et al. A novel serogenetic approach determines the community prevalence of celiac disease and informs improved diagnostic pathways. BMC Med. 2013;11:188.

7. Burden M, Mooney PD, Blanshard RJ, et al. Cost and availability of gluten-free food in the UK: in store and online. Postgrad Med J. 2015;91(1081):622-6.

8. Shah S, Akbari M, Vanga R, et al. Patient perception of treatment burden is high in celiac disease compared with other common conditions. Am J Gastroenterol. 2014;109(9):1304-11.

9. Edwards George JB, Leffler DA, Dennis MD, et al. Psychological correlates of gluten-free diet adherence in adults with celiac disease. J Clin Gastroenterol. 2009;43(4):301-6.

10. Leffler DA, Edwards-George J, Dennis M, et al. Factors that influence adherence to a gluten-free diet in adults with celiac disease. Dig Dis Sci. 2008;53(6):1573-81.

11. Villafuerte-Galvez J, Vanga RR, Dennis M, et al. Factors governing long-term adherence to a gluten-free diet in adult patients with coeliac disease. Aliment Pharmacol Ther. 2015;42(6):753-60.

12. Whitaker JK, West J, Holmes GK, Logan RF. Patient perceptions of the burden of coeliac disease and its treatment in the UK. Aliment Pharmacol Ther. 2009;29(10):1131-6.

13. Hall NJ, Rubin G, Charnock A. Systematic review: adherence to a gluten-free diet in adult patients with coeliac disease. Aliment Pharmacol Ther. 2009;30(4):315-30.

14. Mahadev S, Gardner R, Lewis SK, et al. Quality of life in screen-detected celiac disease patients in the United States. J Clin Gastroenterol. 2016;50(5):393-7.

15. Burger JPW, de Brouwer B, IntHout J, et al. Systematic review with meta-analysis: Dietary adherence influences normalization of health-related quality of life in coeliac disease. Clin Nutr. 2017;36(2):399-406.

16. Sainsbury K, Marques MM. The relationship between gluten free diet adherence and depressive symptoms in adults with coeliac disease: A systematic review with meta-analysis. Appetite. 2018;120:578-88.

17. Kwasnicka D, Dombrowski SU, White M, Sniehotta F. Theoretical explanations for maintenance of behaviour change: a systematic review of behaviour theories. Health Psychol Rev. 2016;10(3):277-96.

18. Sainsbury K, Halmos EP, Knowles SR, et al. Maintenance of a gluten free diet in coeliac disease: The roles of self-regulation, habit, psychological resources, motivation, support, and goal priority. Appetite. 2018;*in press*.

19. Leffler D, Dennis M, Edwards George J, et al. A validated disease-specific symptom index for adults with celiac disease. Clin Gastroenterol Hepatol. 2009;7(12):1328-34.

20. Dorn SD, Hernandez L, Minaya MT, et al. The development and validation of a new coeliac disease quality of life survey (CD-QOL). Aliment Pharmacol Ther. 2010;31(6):666-75.

21. Andrews G, Slade T. Interpreting scores on the Kessler Psychological Distress Scale (K10). Aust N Z J Public Health. 2001;25(6):494-7.

22. Oakley Browne MA, Wells JE, Scott KM, et al. The Kessler Psychological Distress Scale in Te Rau Hinengaro: the New Zealand Mental Health Survey. Aust N Z J Psychiatry. 2010;44(4):314-22.

23. Victorian Government Department of Human Services. Victorian Population Health Survey 2001. In: Department of Human Services, editor. Melbourne: Rural and Regional Health and Aged Care Services Division; 2002.

24. Leffler DA, Dennis M, Edwards George JB, et al. A simple validated gluten-free adherence survey for adults with celiac disease. Clin Gastroenterol Hepatol. 2009;7(5):530-6.

25. Silvester JA, Weiten D, Graff LA, et al. Is it gluten-free? Relationship between self-reported gluten-free diet adherence and knowledge of gluten content of foods. Nutr. 2016;32(7-8):777-83.

26. Standard 1.2.3 Information requirements - warning statements, advisory statements and declarations, (2016).

27. Standard 1.2.7 - Nutrition, health and related claims, (2016).

28. Sainsbury K, Mullan B, Sharpe L. A randomized controlled trial of an online intervention to improve gluten-free diet adherence in celiac disease. Am J Gastroenterol. 2013;108(5):811-7.

29. Sainsbury K, Mullan B, Sharpe L. Gluten free diet adherence in coeliac disease. The role of psychological symptoms in bridging the intention-behaviour gap. Appetite. 2013;61(1):52-8.

30. Silvester JA, Graff LA, Rigaux L, et al. Symptomatic suspected gluten exposure is common among patients with coeliac disease on a gluten-free diet. Aliment Pharmacol Ther. 2016;44(6):612-9.

31. Zingone F, Swift GL, Card TR, et al. Psychological morbidity of celiac disease: A review of the literature. United European Gastroenterol J. 2015;3(2):136-45.

32. Anderson RP, Henry MJ, Taylor R, et al. A novel serogenetic approach determines the community prevalence of celiac disease and informs improved diagnostic pathways. BMC Med. 2013;11:1-13.

33. Cook HB, Burt MJ, Collett JA, et al. Adult coeliac disease: prevalence and clinical significance. J Gastroenterol Hepatol. 2000;15(9):1032-6.

34. Kurppa K, Collin P, Mäki M, Kaukinen K. Celiac disease and health-related quality of life. Expert Rev Gastroenterol Hepatol. 2011;5(1):83-90.

35. Sainsbury K, Mullan B, Sharpe L. Reduced quality of life in coeliac disease is more strongly associated with depression than gastrointestinal symptoms. J Psychosom Res. 2013;75(2):135-41.

36. Halmos EP, Di Bella C, Webster R, et al. Presence of gluten in gluten-free food provided by food businesses: a cross-sectional Australian study. Med J Aust. 2018;*in press*.

37. Biesiekierski JR, Newnham ED, Shepherd SJ, et al. Characterization of adults with a self-diagnosis of nonceliac gluten sensitivity. Nutr Clin Pract. 2014;29(4):504-9.

38. Tye-Din JA, Cameron DJS, Daveson AJ, et al. Appropriate clinical use of human leukocute antigen typing for coeliac disease: an Australasian perspective. Internal Med J. 2015;45(4):441-50.

39. Ludvigsson JF, Bai JC, Federico B, et al. Diagnosis and management of adult coeliac disease:guidelines from the British Society of Gastroenterology. Gut. 2014;63(8):1210-28.

40. Rubio-Tapia A, Hill ID, Kelly CP, et al. ACG Clinical Guidelines: Diagosis and management of celiac disease. Am J Gastroenterol. 2013;108:656-76.

Table 1. Diagnosis and management of coeliac disease in 7044 people with coeliac disease who consented and participated in a survey distributed amongst Australians and New Zealanders

Characteristic	Options	n (%)
How coeliac disease was diagnosed	Coeliac serology only	472 (7)
	Small bowel biopsy only	2609 (37)
	Both serology & small bowel biopsy	3312 (47)
	Neither – based only on symptoms and/or genetic testing	176 (2)
	No response	475 (7)
What led to coeliac disease diagnosis	Symptoms	3591 (51)
	Associated medical condition	1658 (24)
	Family history screening	473 (7)
	Incidental	847 (12)
	No response	475 (7)
Regular review with medical professional	No	2599 (37)
	Yes	3970 (56)
	No response	475 (7)
Source of gluten-free diet information	General dietitian	2297 (33)
	Dietitian specialising in coeliac disease	1690 (24)
	No dietitian	2582 (37)
	No response	475 (7)
Membership to Coeliac Australia/Coeliac New Zealand	Yes	4782 (68)
	No, lapsed member	699 (10)
	No, never been member	817 (12)
	No response	746 (11)
Symptoms after gluten ingestion	No	851 (12)
	Yes, mild	1007 (14)
	Yes, moderate	1823 (26)
	Yes, severe	2365 (34)
	Unsure	523 (7)
	No response	475 (7)
Co-morbidities	Osteoporosis/osteopenia	1676 (24)
	Iron deficiency	1420 (20)
	Other autoimmune disease	1370 (19)
Following a gluten-free diet	Yes	6481 (92)
	No	53 (1)
	No response	510 (7)
Ingestion of oats	No	6058 (86)
	Yes	127 (2)
	Yes, only wheat-free	349 (5)
	No response	510 (7)

Table 2. Logistic regression model showing independent predictors of adherence to a gluten-free diet in 5310 Australians and New Zealanders with coeliac disease

Variable	Gluten-free diet adherence (%)	Coefficient estimate	Estimated OR	P value
Female	**61**	**-0.209**	**0.811**	**0.018**
Age*	**61**	**0.009**	**1.01**	**< 0.001**
Caucasian	61	0.497	1.64	0.121
Level of education completed:				
Secondary school	62	0.028	1.03	0.819
TAFE course/equivalent	59	0.043	1.04	0.711
Bachelor degree	62	0.084	1.09	0.451
Masters degree or higher	66	0.138	1.15	0.204
Household annual income:				
$50 000 - $100 000	60	-0.025	0.976	0.778
$100 000 - $200 000	61	0.018	1.02	0.842
> $200 000	68	0.132	1.14	0.307
Reason for investigations†:				
Associated medical condition	64	0.092	1.10	0.241
Family history screening	59	-0.023	0.977	0.853
Incidental	60	-0.066	0.937	0.521
Symptoms after gluten exposure±:				
No	60	-0.150	0.861	0.208
Moderate	**61**	**0.369**	**1.45**	**< 0.001**
Severe	**61**	**0.458**	**1.58**	**< 0.001**
Unsure	**65**	**0.379**	**1.46**	**0.008**
Knowledge score*	**61**	**0.171**	**1.19**	**< 0.001**
Kessler Psychological Distress Scale*	**61**	**-0.167**	**0.846**	**< 0.001**

OR Odds ratio

Adherence is based on a Celiac Dietary Adherence Test score of < 13

Statistically significant predictors are shown in bold. Higher Kessler Psychological Distress Scale indicates greater likelihood of psychological distress

* Continuous variable

† Compared to symptoms

± Compared to mild symptoms

Table 3. Multivariate analysis, using a multiple linear regression model showing independent predictors of quality of life according to the validated Coeliac Disease Quality of Life score in 5310 Australians and New Zealanders with coeliac disease. Higher Coeliac Disease Quality of Life score indicate poorer quality of life.

Variable	Coefficient estimate	P value
Female	-0.137	0.773
Age*	**-0.138**	**< 0.001**
Caucasian	-0.518	0.780
Level of education completed:		
Secondary school	0.156	0.813
TAFE course/equivalent	0.904	0.151
Bachelor degree	-0.167	0.784
Masters degree or higher	-0.765	0.196
Household annual income:		
$50 000 - $100 000	0.477	0.320
$100 000 - $200 000	0.060	0.906
> $200 000	0.084	0.904
Reason for investigations†:		
Associated medical condition	0.346	0.419
Family history screening	-0.229	0.743
Incidental	0.975	0.082
Symptoms after gluten exposure±:		
No	0.399	0.551
Moderate	**1.17**	**0.035**
Severe	**3.05**	**< 0.001**
Unsure	**2.09**	**0.007**
Knowledge score*	-0.098	0.437
Kessler Psychological Distress Scale*	**1.14**	**< 0.001**
Adherence	**-3.25**	**< 0.001**

Statistically significant predictors are shown in bold

Higher Kessler Psychological Distress Scale indicates greater likelihood of psychological distress

Adherence is based on a Celiac Dietary Adherence Test score of < 13

* Continuous variable

† Compared to symptoms

± Compared to mild symptoms

Figure legend

Figure 1. Flow diagram describing participation in a survey aimed at Australians and New Zealanders with coeliac disease

Figure 2. Self-assessment of ability to adequately apply a gluten-free diet compared to percentage of correctly identifying gluten containing and gluten-free ingredients in 6312 people with coeliac disease. There are significant differences among correct identification of ingredients in the groups of patients who rated themselves as 'excellent', 'good' and 'fair' knowledge (chi-squared analysis).

Figure 3. Estimated adherence probability in people with coeliac disease across a) different age groups, and b) varying Kessler Psychological Distress Scale. Adherence was different amongst categories (chi-squared analysis). Categories for Kessler Psychological Distress Scale scores < 20 indicates likely to be well, 20-24 indicates likely to have a mild mental disorder, 25-90 indicates likely to have a moderate mental disorder and ≥ 30 likely to have a severe mental disorder.

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.