Intentional and inadvertent non-adherence in adult coeliac disease: a cross-sectional survey

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ABSTRACT

Adherence to a gluten-free diet is the mainstay of treatment for coeliac disease. Non-adherence is common as the diet is restrictive and can be difficult to follow. This study aimed to determine the rates of intentional and inadvertent non-adherence in adult coeliac disease and to examine the factors associated with both. A self-completion questionnaire was mailed to adult coeliac patients identified from the computer records of 31 family practices within the North East of England. We received 287 responses after one reminder. Intentional gluten consumption was reported by 115 (40%) of respondents. 155 (54%) had made at least one known mistaken lapse over the same period and 82 (29%) reported neither intentional nor mistaken gluten consumption. Using logistic regression analysis, low self-efficacy, perceptions of tolerance to gluten and intention were found to be independently predictive of intentional gluten consumption. A statistical model predicted 71.8% of cases reporting intentional lapses. Intentional non-adherence to the GFD was found to be common but not as frequent as inadvertent lapses. Distinguishing the factors influencing both intentional and inadvertent non-adherence is useful in understanding dietary self-management in coeliac disease.

Key words: coeliac disease, adherence, behaviour, questionnaire, non-adherence, gluten-free diet

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INTRODUCTION

Coeliac disease (CD) is a chronic inflammatory intestinal disorder characterised by a heightened immunological response to ingested gluten in genetically susceptible individuals. Originally a disease of childhood, CD is now more frequently first diagnosed in adults and has a prevalence of around 1% in Europe and the US (Bingley et al, 2004; Dube et al., 2005; Lohi et al, 2007; West, Logan,Smith, Hubbard & Card, 2003) . This change in presentation is partly explained by the increasing use of serological tests for active case-finding and for targeted screening in high risk groups (Collin, 2005; Hin et al, 1999; Jones, 2007; Karponay-Szabo et al., 2005). Advances in diagnostic testing, together with improved recognition of CD (NICE, 2009), have also resulted in an increased number of individuals diagnosed with atypical, minimal or no symptoms (Mulder & Cellier, 2005). The mainstay of treatment for CD is strict life-long adherence to a gluten-free diet (GFD). For most patients, this results in full clinical and histological remission (Holmes & Catassi, 2000) and is associated with improvements in symptoms and quality of life (Midhagan & Hallert, 2003), a decrease in long term health risks and health gains for problems associated with CD such as infertility, fatigue (Siniscalchi et al, 2005), and depression (Hallert & Sedvall, 1983; Hallert et al., 2002; Whitaker, West, Holmes and Logan, 2009). The GFD is restrictive and can be difficult for some patients to follow however and the most common cause of persistent symptoms is gluten consumption (Dewar et al., 2012; Hopper, Hadijvassiliou, Butt & Sanders, 2007). This is compounded by confusing food labelling and the expense and limited availability of GF foods despite their availability on prescription in the UK and other European countries and increasing availability of GF foods in supermarkets. Adherence to the GFD is reported to range between 36%-96% and is associated with a variety of demographic, psychosocial and clinical factors (Ford, Howard & Oyebode, 2012; Hall, Rubin & Charnock, 2009; Sainsbury & Mullan, 2011). Adherence is not usually conceptualised in behavioural terms, despite the acknowledgement of both

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intentional and inadvertent gluten consumption within the literature (Black & Orfila, 2011; Casellas, Lopez & Malagelada, 2006; Dewar et al., 2012; Vahedi et al., 2003). No study has specifically examined the factors associated with each type of non-adherence in coeliac disease. Although the primary concern in terms of clinical outcomes is actual gluten consumption, greater understanding of these very different behaviours is important in understanding dietary self-management and may inform potential interventions. This study investigates the factors associated with both intentional and inadvertent gluten consumption in adults with CD.

METHODS

A total of 31 family group practices in North East England, covering both rural and urban areas, participated in the study. Using Read code searches of their computerised clinical records, they identified all adult coeliac disease patients, to whom they then posted a self-completion questionnaire (n= 566). A reminder was sent 10-14 days after the initial mailing. The response rate was 53.9% (n=305). Ten participants reported not having been diagnosed with coeliac disease, 7 responses were received after analysis had started and 1 respondent was under 18 years. These were excluded from the analysis, leaving 287 useable responses. All necessary ethical and research governance approvals to carry out the study were gained from the relevant ethics committees and primary care trusts. We did not have ethics approvals to gather data on non-responders. Demographic characteristics of the respondents are reported in table 1.

Table 1 Respondent characteristics

In the absence of appropriate existing measures at the time of the study, the self-completion questionnaire was developed based on findings from a qualitative study which used interviews and focus groups with adults with coeliac disease examining

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influences on adherence to the GFD (Hall, 2010), concepts from health behaviour theory (Ajzen, 1991; Bandura, 1986; Bandura, 2000) and existing literature on adherence in coeliac disease (Hall et al, 2009). Constructs from each source were compared and contrasted and resulted in the following theory-informed concepts being included in the questionnaire: attitudes; physical, social and self-evaluative outcome expectations; self-efficacy; perceptions of control; intention to adhere; perceived difficulties; and treatment and illness beliefs, including perceived tolerance to occasional gluten consumption. Where appropriate, the measurement of concepts and question formatting was based on standard recommendations (Ajzen, 2006). Items included within the scales were elicited from findings from the above mentioned exploratory qualitative study. Table 2 provides examples of the items used within each scale included within the final analysis. Self-reported adherence was measured by asking respondents to indicate the frequency of their intentional and mistaken gluten consumption over the last 6 months using an ordinal scale from every day to never. An indication of the gluten containing foods consumed was also requested. A pilot questionnaire was administered to 20 volunteers from a local coeliac support group and improvements were made based on their responses.

Table 2 Questionnaire constructs

Socio-demographic details were also recorded along with information on symptoms experienced, healthcare, prescription use and membership of Coeliac UK (a charity working for people with coeliac disease in the UK).

Analysis

The statistical package SPSS v14 was used for data analysis. Factor analysis was used to ensure that scales or subscales included the most appropriate items. Cronbach alpha coefficients for all scales used in the analysis were greater than 0.7.

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Because the data were not normally distributed, we used non-parametric tests for statistical analysis. Spearman correlation coefficients were calculated to examine relationships between variables. The questionnaire included two open ended questions. The first asked the participations to state the main reasons for sticking to a GFD and the second asked what would make sticking to the GFD easier for them. A coding frame was developed to categorise these responses based on a thematic analysis.

Logistic regression analyses were used to determine the influence of selected variables on the likelihood of intentional and inadvertent gluten consumption. Two separate logistic regression models were run, the first based on intentional consumption and the second on inadvertent consumption. Self-reported responses indicating that gluten had been consumed over the last 6 months (intentionally for model 1 and inadvertently for model 2) were coded as 1 and all other responses coded as 0. Other definitions of adherence from the literature were considered, however, this was felt to be the most appropriate due to the data distribution and the high median value. Moreover, differentiating those participants who report never intentionally deviating from the GFD and those who do, regardless of the frequency, was considered to be an important distinction when trying to explore the significance of the variables in predicting behaviour and intention. To maintain consistency, the same cut off points were used for mistaken lapses. Respondents who reported having made any mistakes in the last 6 months were compared to those who had not, regardless of the frequency of lapses. Variables showing significant correlations to the outcome variable were included in the regression models.

RESULTS

One hundred and fifteen (40.1%) respondents reported having intentionally consumed gluten consumption over the last 6 months, of whom 102 (88.7%) also reported

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inadvertent gluten consumption. Overall 155 (54.0%) had mistakenly consumed gluten at least once over the same period. 71 (24.7%) had not intentionally consumed gluten, and had made only one or two mistakes. Eighty two (28.6%) reported not having consumed gluten either intentionally or inadvertently. See Fig 1.

Fig 1 Self reported gluten consumption

Some respondents (n=19, 7%) reported being unable to identify whether they had consumed gluten inadvertently. Two hundred and forty three (84.7%) respondents reported that they intended to keep very strictly to their GFD, while 48 (16.7%) reported wanting to be stricter with their GFD than they had been in the previous 6 months. When asked about their adherence since being diagnosed, only 45 respondents (15.7%) strongly agreed with the item "I have never mistakenly eaten any gluten", whereas 133 (46.3%) strongly agreed with the item "I have never intentionally eaten any gluten". Responses to these items are summarised in Fig 2.

Fig 2 Difference between intentional and inadvertent gluten consumption since diagnosis

Overall, attitudes to the GFD were positive and 217 (75.6%) of respondents ranked their GFD as being important, 232 (80.8%) as necessary, and 210 (73.2%) as essential (point 1 on a 7 point semantic differential scale). Scores were more evenly distributed on items asking respondents to rank how easy/difficult or simple/complicated they felt their GFD was (see Fig 3).

Fig 3 Attitudes to the GFD

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Intentional gluten consumption was significantly lower in those who were members of Coeliac UK (n=240 vs n=47, p<0.001), those under regular follow-up (n=185 vs n=97, p<0.01), those receiving GF foods on prescription (n=247 vs n=40, p<0.01) and those diagnosed as adults (n=247 vs n=40, p=<0.05). No significant differences were found for any of these groups in terms of reported inadvertent gluten consumption. Statistically significant but weak correlations were found between some socio-demographic variables and inadvertent gluten consumption but not for intentional consumption (Time since diagnosis, r_s=0.144, p=0.019, n=264; education, r_s= -0.125, p=0.047, n=255; age at diagnosis, r_s=0.149, p=0.016, n=264; and current age, r_s=0.261, p<0.001, n=269). No significant differences were found in intentional or inadvertent gluten consumption between males and females or between those who reported being asymptomatic at diagnosis and those who had experienced symptoms. Reported severity of symptoms prior to diagnosis was, however, correlated with higher intention to adhere to the GFD (p<0.001).

Significant correlations were found between concepts from behavioural theory and intentional and inadvertent gluten consumption, particularly for self-efficacy beliefs, perceived tolerance to gluten and attitudes to the GFD. These correlations are summarised in table 2.

Analysis of the open questions on reasons for adhering to a GFD identified four main themes. These were to feel better, to avoid symptoms, to maintain future health and to avoid potential complications. When asked what would make sticking to the diet easier, the most frequently cited responses related to better quality, choice, cost and availability of gluten-free food, followed by improved awareness and understanding, clearer and universal product labelling and clearer information when eating out.

Table 3 summarises the findings from the logisitic model predicting intentional gluten consumption. The following variables were entered into the regression: perceived

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likelihood of feeling ill, worry about long term impact, perceived likelihood of feeling guilt/regret, a combined perceived support scale, perceived control, intention to adhere, perceived tolerance to gluten, attitudes to the GFD, self-efficacy (intentional or mistaken) and a combined perceived difficulties scale. The model demonstrated a good fit and successfully predicted 71.8% of cases reporting intentional lapses and 90.4% of those reporting not having intentionally consumed gluten. [$p<0.001$; $R^2 = 0.559$]. Lower scores in intention and self-efficacy and high perceived tolerance to gluten were significant independent predictors of intentional gluten consumption.

Table 3 Logistic regression: Intentional gluten consumption

The same variables were entered into a second model using inadvertent gluten consumption as the outcome variable. All variables remained the same apart from confidence in the ability to not intentionally consume gluten (intentional self-efficacy), which was replaced with confidence in the ability to not inadvertently consume gluten (mistaken self-efficacy), and the deletion of intention to adhere to the GFD. A forced entry model demonstrated an adequate fit, although it was not particularly good at predicting the likelihood of the outcome and is therefore not reported here. Perceived difficulty, worry about long-term impact, perceived likelihood of feeling guilt and self-efficacy were significant independent predictors but only had a limited effect. Adding regular follow-up or Coeliac UK membership to a reduced model that included only the significant independent predictors did not make any significant contribution to the predictive value of either model.

DISCUSSION

This is the first study to characterise intentional and inadvertent non-adherence to a gluten-free diet in patients with coeliac disease. Our findings add to those from other

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studies looking at the association between concepts from existing theories of health behaviour (Ford et al, 2012; Leffler et al., 2008; Sainsbury & Mullan, 2011), by demonstrating the importance of this distinction in understanding adherence to the GFD. Both types of non-adherence are common with only 28% of respondents reporting not having consumed any gluten at all over the last six months and 40% reporting intentional gluten consumption on at least one occasion in the same period. Although previous studies have recognised that non-adherence to the GFD may be intentional or unintentional, this is the first that we are aware of to differentiate the factors associated with these two types of non-adherence.

Our statistical model suggests that low intention, perceptions of individual tolerance to occasional gluten consumption and low confidence in one's ability to stick to the GFD are independently predictive of the odds of self-reported intentional gluten consumption, whereas perceived difficulty was not. However, perceived difficulty is associated with the frequency of mistakes made and the confidence in one's ability to stick to the diet (self-efficacy). A lack of a direct association between the reported difficulty of the GFD and adherence has been found by others (Casellas et al, 2006; Leffler et al., 2007). One UK study found, however, that difficulties such as understanding food labelling, affordability, obtaining GF foods and obtaining enough GF foods on prescription were all significantly associated with compliance, but that this was also dependent upon ethnicity (Butterworth, Banfield, Iqbal & Cooper, 2004). More recent research suggests that perceived difficulty is associated with quality of life rather than compliance (Barratt, Leeds & Sanders, 2011).

Some respondents felt they were able to tolerate small amounts of gluten or take more risks in certain situations and these beliefs were independently associated with intentional gluten consumption beyond intention. This finding is compatible with clinical studies that have demonstrated individual variation in reaction to gluten and have generated controversy over thresholds for harm (Collin, Maki & Kaukinen, 2007;

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Viljamaa et al., 2005). Furthermore, even within the scientific community there is lack of agreement over what constitutes a strict GFD, for example, in relation to some foods such as different strains of oats (Comino et al., 2011).

The questionnaire had good face validity when tested, the questions being assessed as relevant, reasonable, unambiguous and clear by patients with coeliac disease and a clinician. The design of the questionnaire was based on established constructs from existing theory and incorporated items elicited from exploratory qualitative research. All scales with more than one item were assessed statistically for internal consistency and reliability. The study recruited a large community sample of people with CD, avoiding the biases associated with recruitment in secondary care or from members of patient societies. The response rate of 53.9%, was lower than some questionnaire studies carried out in secondary care and coeliac society populations, but respondent characteristics in terms of gender and age are comparable (Bebb, Lawson, Knight & Long, 2006; Edwards George et al, 2009). We were not able to directly compare characteristics of our sample with those of non-responders, however, and we cannot therefore rule out bias.

Limitations of the study are its cross-sectional design, the reliance upon self-reported measures and the use of a questionnaire that had not been previously validated. Our results should therefore be interpreted with caution and require validation by further research. It is not possible to infer causality and we cannot conclude, for example, whether a greater level of perceived difficulty is associated with more inadvertent lapses, or whether awareness of inadvertent lapses results in greater perceived difficulty, a higher self-reported gluten consumption and lower confidence in the ability to adhere. Due to resource implications, it was, unfortunately, not possible to validate self-reported adherence with dietetic assessment by an expert or food diaries. This may have identified additional inadvertent gluten consumption, particularly for the minority of respondents who stated they were unable to tell if they had mistakenly

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consumed gluten. Although not always ideal, self-reports of adherence have been shown to correlate to other more objective measures in other studies (Biagi et al. 2012, Leffler et al., 2007; 2009). Our data demonstrates that the majority of respondents were able and willing to self-report their adherence in this way and the anonymous nature of the questionnaire may have for facilitated the admission of intentional lapses for some respondents. The description of foods consumed intentionally also highlights the difficulty of soley using a frequency based measure of adherence in this situation. Gluten containing foods reported to have been consumed ranged from wheat flour based cakes or biscuits to occasional consumption of non-wheat based cereal brands or foods containing oats. Comparing reported adherence with other studies is difficult as research to date has used a range of different measures and definitions of strict adherence. Measures are often defined in terms of frequency of gluten consumption rather than quantities and distinguishing mistaken and intentional gluten consumption is not common practice. For this study, adherence rates could reasonably be reported to be between 28% and 88% depending on the definition used.

Furthermore, assessment of the level of non-adherence at which possible interventions would be deemed to be most beneficial is also problematic, as the potential individual and societal health benefit of small changes in gluten consumption is difficult to estimate. The risk of malignancy, for example, is now believed to be much lower than previously estimated and the influence of occasional non-adherence is unclear (Akobeng & Thomas, 2008; Catassi et al., 2007; Green et al., 2003; Haines, Anderson, & Gibson, 2008; Kaukinen et al., 1999; Silano et al., 2007). Diagnostic delay may have an influence on the likelihood of long term complications beyond treatment adherence (Silano et al., 2007) although the evidence for this is mixed (Haines et al., 2008).

Another limitation of our study was that no objective measure was taken of understanding and knowledge of the GFD. It is possible that knowledge and the ability

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to read food labels correctly may contribute towards the prediction of inadvertent gluten consumption in particular. This association may be complicated by by the inability of some individuals, such as those who do not experience symptoms, to know when they have inadvertently consumed gluten. Differentiating those who report intentionally consuming gluten from those who don't can be helpful in terms of understanding the more behavioural aspects of dietary self-management, however, we acknowledge that this is not necessarily reflective of actual gluten consumption, especially for those with poor understanding or knowledge. In light of the high levels of generally positive attitudes towards treatment found in our study, attempts to improve knowledge or skills alone may have little impact on intentional non-adherence.

Additional factors not included in this study might have improved the predictive value of our statistical model. In one US study of the psychological correlates of adherence to the GFD, conscientiousness explained a high proportion of adherence to the GFD (Edwards George et al., 2009). Ethnicity and other socio-cultural factors may also be associated with adherence (Butterworth et al., 2004) particularly in light of wider research describing socio-cultural differences in attitudes to food and food choice behaviour (Moon, Quaredon, Barnard, Twigg & Blyth,, 2007; Pettinger, Holdsworth & Gerber, 2004; Rozin, 1996), and contradictory research findings regarding quality of life in coeliac disease across Europe. The majority of our respondents received GF food on prescription, for example, and this may be an important element differs between countries and is subject to local differences in health policy. Further research on the influence of wider cultural and social factors may be valuable in describing and understanding adherence to the GFD. Finally, our findings do not differentiate between the awareness of potential consequences of non-adherence and individual motivation to avoid them. These differences have not been well addressed in previous CD research and were insufficiently defined in our own questionnaire.

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CONCLUSION

Distinguishing between intentional and unintentional gluten consumption is important in understanding dietary self-management in CD. Mistaken gluten consumption is more frequent than intentional consumption and these two types of non-adherence are explained by different factors. Constructs from social cognitive models of health behaviour usefully predict intentional gluten consumption but are less useful for inadvertent consumption. Our findings suggest that interventions based on theories of health behaviour may be of benefit in addressing elements of intentional non-adherence for a minority of coeliac patients and may have some impact on mistaken non-adherence caused by risk-taking in certain situations. Mistaken non-adherence, however, may be mostly a result of circumstances outside of the control of the individual and is associated with lower levels of self-efficacy and increased levels of perceived difficulty, the latter of which has been associated with lower quality of life. Strict adherence to the GFD requires a range of knowledge, skills and complex behaviours in order to avoid all sources of gluten. It is therefore important to also acknowledge and continue those efforts to facilitate dietary self-management in CD which extend beyond the individual and the health care setting, such as continued improvements in food labelling, the increasing provision of GF foods within supermarkets and increased awareness within the catering and food manufacturing industry.

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Figure 1 Reported intentional and inadvertent gluten consumption (n=269)

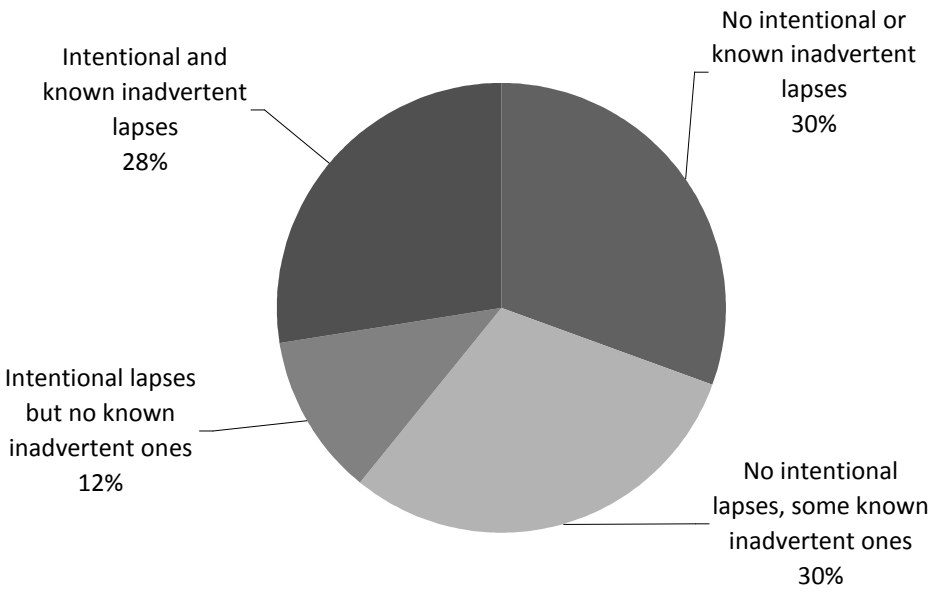

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Figure 2 Perceived intentional and inadvertent gluten consumption since diagnosis (7 point Likert scale)

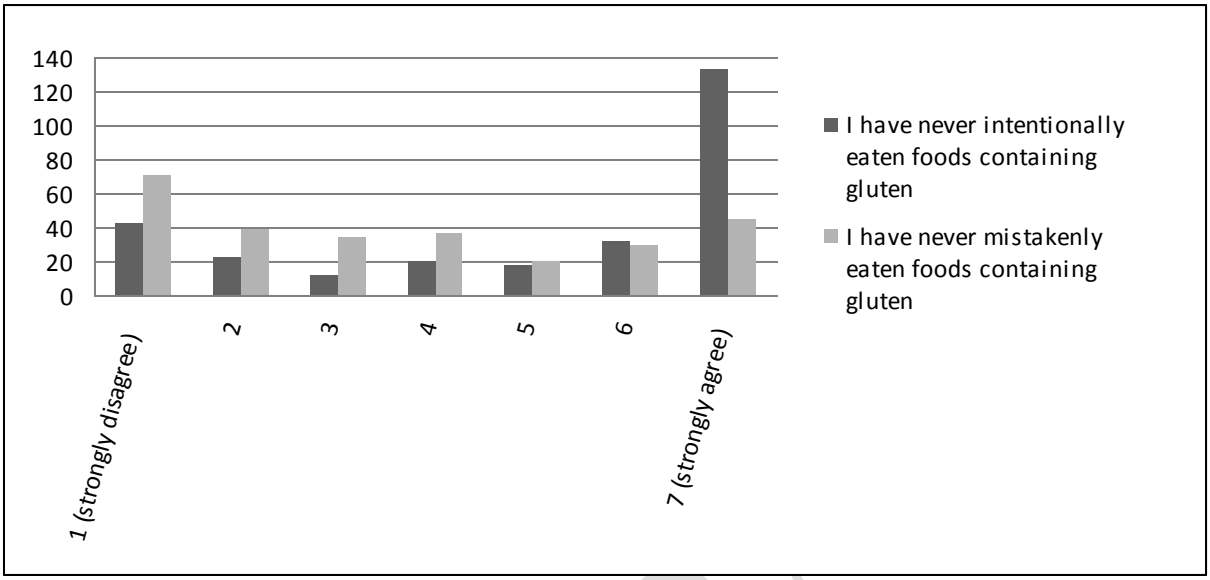

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Figure 3 Attitudes to the GFD (Semantic differential scales)

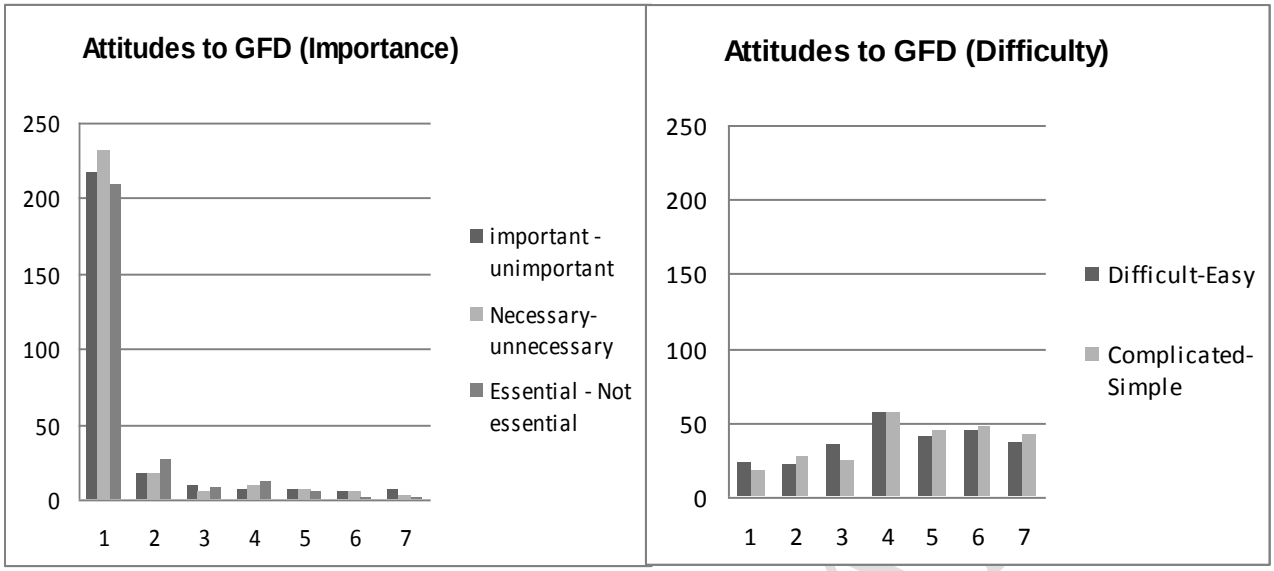

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Table 1 Respondent characteristics

Respondent Characteristics	*Total sample (N=287)*
Sex	
Female	208 (72.5%)
Male	79 (27.5%)
Age (mean years; SD)	56.17 (14.62)
Age at diagnosis (mean years; SD)	41.61 (20.34)
Time since diagnosis (mean years; SD)	14.45 (15.48)
Educational qualifications	
None	71 (24.7%)
Secondary school education or vocational	93 (32.4%)
Post 16 education	44 (15.3%)
University level or above	71 (24.7%)
No response	8 (2.8%)
In receipt of GF food on prescription	247 (86.1%)
Member of Coeliac UK	240 (83.6%)
Under regular follow-up	185 (64.5%)
Under regular follow-up with dietician	67 (23.3%)
Symptoms	
Symptomatic before diagnosis*	180 (62.7%)
Presence of "classic" symptoms before diagnosis*	142 (49.5%)
Currently experiences symptoms after eating gluten	202 (70.4%)

* those diagnosed in childhood may have been unaware of symptoms prior to diagnosis.

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Table 2 Questionnaire constructs and correlation coefficients

Scale / variable	**N items**	**Example item (7 point scales)**	**Correlation to intention to adhere strictly** (Spearman correlation coefficients)	**Correlation to intentional gluten consumption** (Spearman correlation coefficients)	**Correlation to inadvertent gluten consumption** (Spearman correlation coefficients)
Self-evaluative outcome	2	If I ate food containing gluten, I would feel guilty (not at all likely .. very likely)	0.298***	-0.272***	ns
Perceived social support	10	Whose support do you value in regards to your GFD? e.g. close family (not at all.. very much)	0.285***	-0.229***	ns
Perceived difficulty scale	10	Confusing food labels (not at all a difficulty for me.. particularly difficult for me)	ns	0.132*	0.253***
Likelihood of feeling ill	1	If I ate food containing gluten, I would feel ill soon after (not at all likely .. very likely)	0.354***	-0.271***	ns
Worry long term impact	1	If I ate food containing gluten, I would worry about the long term impact on my body (not at all likely .. very likely)	0.252***	-0.145*	ns
Perceived tolerance to gluten	4	I am able to cope with an occasional gluten-containing treat (strongly disagree.. strongly agree)	-0.482***	0.521***	ns
Attitude	3	For me, sticking to a GFD is important…unimportant	-0.560***	0.458***	0.175***
self-efficacy (intentional lapses)	4	How confident are you in your ability to not eat foods you know contain gluten when e.g. eating out (no confidence... complete confidence)	0.520***	-0.491***	-0.352***
Self-efficacy (mistaken lapses)	2	How confident are you that you will not mistakenly eat gluten when e.g. eating out (no confidence... complete confidence)	0.355***	-0.355***	-0.378***
Perceived control	1	How much personal control do you feel you have over your condition (no control.. complete control)	0.436***	-0.297***	-0.184**

P<0.001*** p<0.01** p<0.05* ns=non significant

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Table 3 Logistic regression: Intentional gluten consumption

Total sample (n=276)	**Odds Ratio (OR)**	**[95.0% CI]**	
Variables included		**Lower**	**Upper**
self-evaluative outcome	.097	0.88	1.06
social support	0.89	0.73	1.07
perceived difficulty	1.09	0.80	1.50
likelihood feeling ill	1.08	0.88	1.32
worry long term impact	1.04	0.85	1.28
perceived tolerance	1.73***	1.33	2.25
attitude (importance)	0.90	0.58	1.39
self-efficacy (intentional)	0.59**	0.41	0.85
intention	0.18***	0.08	0.39
control	1.33	0.85	2.09

P<0.001*** p<0.01** p<0.05*
Smallest category=intentionally non adherent (1) = 110
Model Chi ^{2} (10) = 147.131, p<0.001; -2LL= 224.045; Hosmer and Lemeshow goodness of fit Chi ^{2} (8) = 6.882, p=0.549
R^2= 0.413 (Cox & Snell), 0.559 (Nagelkerke).
C statistic = 0.830, sensitivity=71.8%, specificity= 90.4%

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