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Research report

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.

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 et al., 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, Bird, Fisher, Mahy, & Jewell, 1999; Jones, 2007; Korponay-Szabo et al., 2005). Advances in diagnostic testing, together with improved recognition of CD (National Institute for Health, 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 (Midhagen & 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, & 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, Hadjivassiliou, 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% and 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 intentional and inadvertent gluten consumption within the literature (Black & Orfila, 2011; Casellas, Lopez, & Malagelada, 2009; 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

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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, seven 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.

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 influences on adherence to the GFD (Hall, 2010), concepts from health behaviour theory (Ajzen, 1991; Bandura, 1986, 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 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[a]	180 (62.7%)
Presence of "classic" symptoms before diagnosis[a]	142 (49.5%)
Currently experiences symptoms after eating gluten	202 (70.4%)

[a] Those diagnosed in childhood may have been unaware of symptoms prior to diagnosis.

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.

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.

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 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.

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