

Measuring beliefs about gluten free diet adherence in adult coeliac disease using the theory of planned behaviour

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Abstract

The theory of planned behaviour (TPB) was used to elicit the salient beliefs about gluten free diet (GFD) adherence in adults with coeliac disease (CD) and to design a TPB questionnaire to predict adherence levels. This questionnaire was administered to 265 CD participants with adherence and quality of life (QOL) measures, a GFD knowledge test, and self-reported psychiatric history. Regression analyses were used to test the fit of the TPB in predicting adherence, and to determine the nature of the relationships between adherence, QOL, knowledge, and psychiatric history. The TPB combined with self-reported depression and anxiety, and QOL explained significant variance in intention (39.4%) and adherence (36.4%). Poorer dietary adherence and psychiatric history were also associated with lower QOL. Findings suggest that the TPB provides an adequate model for predicting GFD adherence in CD, and the presence of psychiatric conditions represents a potential intervention target to improve adherence and QOL.

Key words: coeliac disease, gluten free diet, adherence, theory of planned behaviour

Introduction

Coeliac disease (CD) is a chronic autoimmune disorder in which the body is unable to effectively digest gluten, the protein found in wheat, rye, barley, and in some countries including Australia, oats. Ingestion of dietary gluten in individuals with CD causes villous atrophy of the small intestine, and results in symptoms such as cramping, bloating, nausea, diarrhoea, iron deficiency anemia, fatigue, weight loss, and vitamin and mineral deficiencies (Green, & Cellier, 2007). CD is a genetic condition and affects approximately 1% of the population, although it is estimated that a large number of people remain undiagnosed. The only treatment for CD at present is a strict lifelong gluten free diet (GFD), as even trace amounts of gluten are sufficient to cause an immune response (Rubio-Tapia, & Murray, 2010). Adherence to the GFD is essential not only for preventing the immediate occurrence of gastrointestinal symptoms, but also in reducing the risk of developing long-term health complications such as intestinal and bowel cancers, osteoporosis, and female and male infertility (Green, & Jabri, 2000).

Strict adherence to the GFD in CD has been estimated at between 40 and 90% depending on the method of evaluation and definition of strict adherence (Hall, Rubin, & Charnock, 2009). Due to the importance of strict adherence in CD, numerous researchers have investigated the factors related to GFD non-adherence in order to identify potential intervention targets to improve adherence levels in non-adherent individuals. To date, however, there has been a paucity of actual intervention studies and it is yet to be seen whether the factors identified as correlated with non-adherence can be successfully targeted to improve adherence. A systematic review of 38 adherence studies conducted by Hall and colleagues (2009) found that the most commonly reported correlates of GFD adherence fell into the broad categories of cognitive

(knowledge, attitudes, and illness representations), emotional (anger, depression, and anxiety), and sociocultural influences (public awareness, dining out, travel, and social events), as well as membership of an advocacy group, and regular dietetic follow-up. Another large study found that GFD adherence was influenced by perceptions of the GFD (akin to the attitude component of this study), the ability to follow the diet outside the home, and the ability to maintain adherence despite changes in emotional state such as mood and stress (Leffler et al., 2008). Sociodemographic variables such as age, gender, education, and socioeconomic status do not appear to be related to adherence levels (Hall et al., 2009). Numerous studies have also demonstrated a link between poorer GFD adherence and lower quality of life (QOL) in CD (e.g., Casellas et al., 2008; Hauser, Stallmach, Caspary, & Stein, 2007; Usai et al., 2002).

To date, no study has attempted to apply a validated model of health behaviour to the understanding of GFD non-adherence or the difficulties CD individuals encounter when maintaining a strict GFD. The Theory of Planned Behaviour (TPB; Ajzen, 1991) is a widely used model within the field of health psychology and has been successfully applied to the prediction of a number of health behaviours including fruit and vegetable consumption, exercise, leisure choice, and smoking (Armitage & Conner, 2001). The TPB assumes that most behaviour is rational and goal-directed, and people make conscious decisions based on the information available to them (Conner & Armitage, 1998). Specifically, the TPB posits that behaviour is directly related to the intention to perform that behaviour. Intention is, in turn, influenced by an individual's attitudes: beliefs about the likely outcomes of the behaviour (behavioural beliefs) and the desirability of such outcomes; subjective norms: perceptions of the expectations of others (normative beliefs) and motivation to comply with such expectations; and

perceived behavioural control (PBC): beliefs about the factors that facilitate or impede the performance of the behaviour (control beliefs), and the level of control the individual has over these factors; Ajzen, 1991).

This study is the first to apply the TPB to the prediction of GFD adherence and to use a health behaviour model to understand the attitudes and beliefs underlying how CD individuals approach their diets, and the ways in which they negotiate potential difficulties encountered when maintaining the GFD. In this way the present study represents a significant advancement over previous research that has relied on anecdotally driven data collection and failed to utilise the theoretical models known to be useful in predicting health behaviours. A common criticism of the TPB is, however, that it encompasses only the conscious and rational components of decision-making, failing to consider the unconscious and irrational influences on behaviour (Conner & Norman, 2005), such as emotional states, psychological problems and coping skills. For this reason self-reported psychiatric history and QOL were included as potential factors influencing behaviour, but that are not captured by the TPB.

The aim of this study was firstly, to design a questionnaire based on the salient behavioural, normative, and control beliefs associated with maintaining a strict GFD in individuals diagnosed with CD assessed via interview; and secondly, to validate the questionnaire and determine the suitability of the TPB in predicting GFD adherence by administering the purpose designed questionnaire and a measure of adherence to a sample of CD individuals. It was predicted that the TPB would account for significant variance in the prediction of the intention to maintain a strict GFD and actual GFD adherence. Based on previous findings (e.g., Hall et al., 2009; Leffler et al., 2008) it was also predicted that lower levels of GFD knowledge and the presence of a psychiatric

diagnosis would negatively impact GFD adherence. QOL and adherence should also be related, although this relationship is likely bidirectional.

Phase 1: Elicitation Interviews

Method

Participants

The interview respondents were 13 individuals (7 male; mean age = 47.0 (SD = 15.9)) with biopsy confirmed CD who were recruited from the Coeliac Society of NSW. The mean age at diagnosis was 28.9 years (SD = 15.1), and participants had been on a GFD for a mean of 7.8 years (SD = 8.6). The most common symptoms reported prior to diagnosis were cramping/bloating (n = 11); flatulence/abdominal distention (n = 11); fatigue/lethargy (n = 9); diarrhoea (n = 8); anemia (n = 6); and altered mental alertness (n = 6). Six of the participants reported a family history of CD.

Procedure

One-to-one interviews were conducted by the first researcher at the Coeliac Society of NSW in accordance with Ajzen's (2006) and Francis et al.'s (2004) manuals on how to construct a TPB questionnaire using elicitation interviews. Each participant completed a questionnaire including demographic and CD information, before being asked a series of nine standardised interview questions based on the TPB (behavioural beliefs -advantages/disadvantages of maintaining a GFD; normative beliefs - individuals and groups who would approve/disapprove of their GFD; and control beliefs - factors that impede/facilitate their ability to maintain a GFD). Two additional questions were included to assess the circumstances under which participants had not adhered with

their GFD in the past, and the factors they considered when deciding whether or not to adhere to their diet in such situations. There were no limits to the number of responses each participant provided to each question, and interviews lasted between 20 and 30 minutes. All interviews were audio recorded and transcribed verbatim.

Analysis

The participants' responses to the interview questions were content analysed and categorised by the researchers using the predefined categories specified in the TPB (attitudes, subjective norm, perceived behavioural control (PBC)). Within each of the three categories responses were collated and grouped into themes or sub-categories agreed upon by the researchers.

Data saturation and the number of required interviews were determined following the procedure recommended by Francis et al. (2009), in which researchers decide a priori the initial sample size at which analysis will be conducted, and the stopping criterion or point when sampling will cease when no new themes emerge. Consistent with the TPB examples in their paper these limits were set at 10 + 3, to give a minimum sample size of 13. As suggested by Francis et al. (2009) in order to establish data saturation, summary tables were constructed for each of the three TPB categories to show the beliefs mentioned by each interview participant. These tables were used to generate a combined cumulative frequency graph to sequentially reflect the shared beliefs (defined as those mentioned by two or more participants, although most beliefs here were endorsed by at least five participants) elicited in each of the TPB categories, in relation to the specified limits (see figure 1).

Results

Behavioural Beliefs (advantages and disadvantages of maintaining a strict GFD)

The 23 identified advantages and disadvantages of maintaining a strict GFD fell into 16 broad categories, including avoidance of symptoms and long-term health complications, increased subjective well being, restrictions in social situations and food choices when eating away from home, and drawing attention to oneself. Table 1 shows the categories of beliefs elicited in the interviews.

Normative Beliefs (people who would approve/disapprove)

Interestingly the majority of participants initially indicated that the decision to maintain a strict GFD was primarily a personal one, and one which they would have made regardless of the opinions of others. The six additional reference groups cited were families, partners, friends, work colleagues, the coeliac society, and friends/family who also have CD.

Control Beliefs (factors or circumstances that aid/impede)

The 22 control beliefs fell into 14 broad categories including awareness of CD and the GFD from restaurant staff, availability of GF food (e.g., in supermarkets, hotels, restaurants, catered events, and fast food outlets), difficulty trusting non-CD individuals to prepare food, and personal factors such as organisation, and confidence in label reading and asking questions about contamination.

Non-adherence to the GFD in the past (circumstances and motivation)

The most common circumstances that had led to past non-adherence included feeling that they would cause offence or inconvenience other people by not eating, when there were limited options, and taking a small risk when the likelihood of contamination or trace amounts of gluten was unclear. Interestingly, although several participants cited missing out on previously enjoyed foods as a disadvantage, only three respondents said they had not adhered to the diet for this reason. The factors that participants considered when making this decision included the predicted severity and duration of symptoms, the amount of gluten contained in the food in question, and generally weighing up the risks and benefits associated with not adhering to the diet at that time. Several participants also reported a curiosity regarding the effects of eating gluten after having been on the GFD for a period of time.

Table 1 about here

Achieving Data Saturation

The data was analysed after the minimum of 13 interviews had been conducted (Francis et al., 2009), and overall there was a very high agreement between individual participants' responses, with 30 of the 36 categories endorsed by five or more people, and the remaining six categories endorsed by either three or four respondents. Figure 1 shows that a total of 23 behavioural beliefs (grouped into 16 categories), 6 normative beliefs, and 22 control beliefs (grouped into 14 categories) were elicited. Construct-level and study-wise data saturation was achieved prior to the specified minimum sample size, with no new beliefs emerging after interview eight.

Figure 1 about here

Phase 2: Questionnaire Development

TPB Questionnaire

The belief categories endorsed by three or more respondents were converted into statements pertaining to the strength of the belief, as well as the outcome evaluation (attitude), motivation to comply (norms), and power of the belief (PBC) respectively. The final questionnaire consisted of 93 items, including 17 direct measures of intention, attitudes, subjective norm, and PBC, and 76 indirect items derived from the elicitation interviews. All items (direct and indirect) utilised a seven point Likert scale format.

Direct Measures

The direct measures were based on the standard TPB questions suggested by Azjen (2006) and Francis et al. (2004), and in all cases the questions included the stem “maintain a strict gluten free diet.” The direct measures of intention required respondents to indicate the degree to which they expected, wanted, and intended to maintain a strict gluten free diet (three items). For the attitude component respondents indicated their level of agreement on each of five semantic differential scales (harmful/beneficial; pleasant/unpleasant; good/bad; worthless/valuable; enjoyable/unenjoyable). Five items assessed the degree to which respondents felt pressure from other people to perform the behaviour. Finally, the control component of the TPB was assessed using four questions in which respondents rated the possibility of maintaining a strict GFD, and their control and confidence in doing so.

Indirect Measures

For the 16 behavioural belief items respondents were required to indicate the likelihood that each outcome would occur while maintaining a strict GFD (extremely untrue - extremely true); and then to indicate the desirability of each of these outcomes (extremely undesirable - extremely desirable). In addition to the referents identified in the interviews, health professionals were included under normative beliefs, as the literature suggested that the quality of care and information from general practitioners and gastroenterologists in particular, influenced dietary adherence (Case, 2005). For each referent respondents indicated the level of support in their decision to maintain a strict GFD (strongly disagree - strongly agree), and their motivation to comply with the wishes of each referent (not at all - very much). Similarly, for the 14 control belief items respondents were required to indicate the strength of each control factor (strongly disagree - strongly agree), and subsequently, the extent to which each factor would make it more or less difficult for them to maintain a strict GFD (much more difficult - much easier).

Phase 3: Main Study

Method

Participants

The participants were 299 individuals with biopsy confirmed CD who were recruited via an email sent to 1495 members of the Coeliac Society of NSW. As participants were able to submit incomplete questionnaires, 34 participants were excluded due to an insufficient number of questions being answered, while a further 31 had incomplete but sufficient data for inclusion. The final sample consisted of 265 participants (83.4%

female; mean age = 45.1 (SD = 13.0)). The mean age at diagnosis was 36.6 years (SD = 14.6), and participants had been on a GFD for a mean of 8.3 years (SD = 9.4). The most commonly reported symptoms prior to diagnosis were fatigue/ lethargy (79.2%); flatulence/ abdominal distention (75.5%); cramping/ bloating (66.8%); diarrhoea (59.6%); vitamin/ mineral deficiencies (52.8%); and anemia (50.9%). 27% of the sample reported a family history of CD.

Measures

Participants completed the following measures via an online survey: demographic information (e.g., age, gender, education); self-reported psychiatric diagnoses; coeliac disease variables (e.g., age of diagnosis, duration of GFD, symptoms); the TPB questionnaire (described above); a GFD adherence measure; a QOL measure; and a GFD knowledge test.

The Coeliac Dietary Adherence Test (CDAT; Leffler et al., 2009) is a seven-item questionnaire designed to assess GFD adherence in CD. It has been shown to have adequate reliability and face, internal, and external validity, and correlates highly with dietitian rated estimates of adherence (Leffler et al., 2009). The authors suggest that the CDAT can be used alone or in conjunction with biological markers to assess adherence to the GFD. Due to the online design of the present study the CDAT was chosen as the sole measure of adherence.

The Australian World Health Organisation Quality of Life Assessment-Bref (WHOQOL-BREF; Murphy, Herrman, Hawthorne, Pinzone, & Evert, 2000) is a 26-item questionnaire designed to measure health related QOL. It comprises four domains

(physical, psychological, social, environmental) as well as an overall rating of QOL and satisfaction with health (single items).

The GFD Knowledge Test consisted of 14 ingredient lists and required participants to draw on their label reading skills and knowledge of ingredients to state whether each product was GF or not. The test items were adapted from educational materials used by the Coeliac Society of NSW and included ingredients that are commonly found in both GF and regular foods. Participants were instructed not to refer to their ingredient booklet provided by the Coeliac Society that they received upon obtaining membership.

Procedure

The Coeliac Society's database was screened to identify 2874 members who met the following inclusion criteria: biopsy confirmed CD, on a GFD for minimum three months, aged 18-65. An invitation email which included an introduction to the study, a copy of the participant information statement, and a link to the website to complete the online questionnaires was sent to a randomly selected sample of 1495 members meeting inclusion criteria. All data was submitted anonymously, and the questionnaires took approximately 20-30 minutes to complete.

Results

Internal consistency- TPB direct measures

Internal consistency analysis (Cronbach's alpha) indicated that the intention ($\alpha = 0.68$), attitude ($\alpha = .68$), and PBC scales ($\alpha = 0.81$) all had adequate reliability. Subjective norm was less consistent ($\alpha = 0.43$). Subsequent examination of the

correlations between the subjective norm items indicated the highest value consisted of two items: “I feel under social pressure to maintain a strict GFD,” and “When it comes to maintaining a strict GFD, how much do you do what other people think you should?” Using only these two items Cronbach’s alpha increased to 0.50, and thus this two-item composite was used in subsequent analyses.

Computing the indirect measures

In accordance with Francis et al. (2004) the scores on each set of corresponding beliefs were multiplied (i.e., behavioural beliefs x outcome evaluations; normative beliefs x motivation to comply; and control belief strength x control belief power); however, due to the large number of individual beliefs included in the questionnaire, prior to computing the composite scores for each set of beliefs, the correlations of the individual beliefs with intention and adherence were examined. In each case (behavioural, normative, and control) seven items had significant correlations with intention and/or adherence, and thus only these items were summed and weighted to provide the belief-based measures of attitude, subjective norm, and PBC. Table 2 shows the seven items included for each construct and the correlations with intention and adherence.

Table 2 about here

Relationship between the direct and indirect measures, intention, and knowledge

Table 3 shows the means and standard deviations for all the measures, and Table 4 shows the correlations between adherence, the TPB variables (direct and indirect),

QOL, and knowledge. Correlations between each of the corresponding pairs of direct and indirect measures were all positive and significant ($p < .01$), indicating adequate content validity of the indirect measures (Francis et al., 2008). Regression analysis indicated that 9.6% of the variance in attitude was predicted by behavioural beliefs ($F(1, 258) = 27.3, p < .001$). When attitude was, however, divided into separate need (beneficial/harmful, valuable/worthless and good/bad) and like (pleasant/unpleasant, enjoyable/unenjoyable, good/bad) scales, the amount of variance predicted by the behavioural beliefs was significantly higher for need (19.2%) than like (5.4%), probably reflecting the fact that the medical need for a GFD outweighs the potential dislike of the limitations associated with the diet. Despite this, the decision was made to include the overall attitude component, as both needing and liking are important aspects of an overall attitude. 7.6% of the variance in subjective norm was accounted for by normative beliefs ($F(1, 252) = 20.7, p < .001$); and 15.6% of the variance in PBC was accounted for by control beliefs ($F(1, 242) = 44.7, p < .001$).

Bivariate correlations between each of the direct and indirect measures, and intention were positive and highly significant ($p < .01$), with the exception of subjective norm, which was negatively correlated with intention, such that a higher perception of norms was related to lower intentions ($p < .05$). GFD knowledge was not significantly correlated with any of the TPB variables or adherence and so was not included in the subsequent regression analyses.

Table 3 about here

Table 4 about here

Regression analysis predicting intention

A hierarchical regression analysis was conducted to examine the predictors of intention to maintain a strict GFD. The direct measures were entered at step 1, followed by the indirect measures of behavioural, normative and control beliefs (step 2). As self-reported depression and anxiety were the most commonly reported psychiatric diagnoses these were entered at step 3 with overall QOL. The direct measures accounted for 35.4% of the variance in intention ($F(3, 234) = 42.8, p < .001$). The indirect measures added a further 4% to the model ($R^2 = .394, F(6, 231) = 25.0, p < .001$), with attitude, PBC, behavioural, and normative beliefs making significant independent contributions. Depression, anxiety, and QOL did not add to the prediction of intention ($p > .05$) (see Table 5).

Table 5 about here

Regression analysis predicting GFD adherence

A hierarchical regression analysis using intention (step 1), followed by the direct measures (step 2), the indirect measures (step 3), and self-reported depression and anxiety, and QOL (step 4) was conducted to examine the predictors of GFD adherence. Intention accounted for 8.7% of the variance in adherence ($F(1, 236) = 22.7, p < .001$), while the direct and indirect measures accounted for a further 15% and 3.3% of the variance respectively (direct: $R^2 = 0.236, F(4, 233) = 18.0, p < .001$; indirect: $R^2 = 0.269, F(7, 230) = 12.1, p < .001$). Finally, the addition of self-reported depression and anxiety, and QOL added a further 9.5% to the model ($R^2 = 0.364, F(10, 227) = 13.0, p$

< .001). PBC, normative beliefs, depression, and QOL made significant independent contributions (see Table 6).

Table 6 about here

Psychiatric diagnoses

The incidence of self-reported depression (current and past combined) was 40.4%, and self-reported anxiety was 40.8%. Other diagnostic categories endorsed by participants (current and past combined) included post-traumatic stress disorder (8.7%); eating disorders (6%); alcohol or substance abuse or dependence (5.6%); and obsessive compulsive disorder (3.7%). Overall 55.5% of the sample reported suffering from one or more psychiatric conditions.

An independent samples t test showed that the group who reported a psychiatric history had significantly poorer adherence than those without a psychiatric history (no psychiatric history group: $M = 11.8$; $SD = 3.1$; psychiatric history group: $M = 13.5$; $SD = 3.2$; $t(240) = 4.0$, $p < .001$; note: higher scores indicate poorer adherence). Further t tests also showed that the psychiatric group reported lower physical, psychological, and environmental QOL, as well as overall QOL and satisfaction with health, than the group without a psychiatric history ($p < .01$).

Relationship between QOL, adherence, and knowledge

Based on Leffler et al.'s (2009) initial analysis of the CDAT, participant's total scores on the CDAT were classified as excellent or very good, moderate, or fair to poor. The mean and modal scores on the CDAT fell in the excellent or very good range, with

47.5% of the sample reporting excellent or very good adherence; 35.8% reporting moderate adherence; and 7.9% reporting fair to poor adherence (8.8% missing data). Participant's scores on the WHOQOL-BREF physical and psychological domains fell approximately half a standard deviation below Australian population norms, while the social and environmental domain scores and the overall ratings (single items) were consistent with population norms (Murphy et al., 2000). Of the incorrect responses on the GF knowledge test, 30.5% of the decisions would have placed participants at risk of consuming gluten, while the other 69.5% of responses indicated participants were unnecessarily restricting their diets and avoiding products that were in fact GF.

All the WHOQOL-BREF scores were positively and significantly correlated with each other ($p < .01$). CDAT scores and QOL (all domains, overall QOL, and satisfaction with health) were also significantly correlated ($p < .01$) indicating that poorer adherence was associated with poorer QOL. Knowledge scores were only significantly correlated with overall QOL ($p < .05$), although the direction was contrary to expectations, with better knowledge and poorer QOL being related.

Discussion

The overall aim of this study was to predict the level of GFD adherence in adults diagnosed with CD. Overall models accounted for 39.4% of the variance in intention, and 36.4% of the variance in adherence behaviours. While previous research has assessed the numerous factors relating to GFD adherence, there is a lack of rigorous and theory-driven research, as well as large variability in how strict adherence is defined across studies (Hall et al., 2009)

Understanding GFD adherence

The elicitation interviews showed a high level of agreement in participants' responses, with the majority of belief categories being endorsed by five or more participants. Overall, the interview data was largely consistent with previous research. For example, Leffler and colleagues (2008) revealed 13 factors, including the ability to follow the GFD while traveling, dining out, and at social events, the increased cost and reported understanding of the GFD, most of which were directly comparable to this study. Other factors related to adherence found in previous research have included access to GF products, coeliac society membership, clear and consistent food labeling, satisfaction with the taste and texture of GF products, worry about food preparation, and embarrassment at sharing food (Butterworth, Banfield, Iqbal, & Cooper, 2004; Ciacci, D'Agate, de Rosa et al., 2003; Lamontagne, West, & Galibois, 2001), most of which were also elicited here.

Examination of the specific behavioural beliefs showing significant correlations with intention and adherence indicated that the advantages of maintaining a strict GFD appeared to be a bigger motivator than the disadvantages. This finding is consistent with a study by Astrom and Rise (2001), who found that their sample made decisions about healthy eating on the basis of the associated *positive* consequences and lack of difficulty in doing so. Interestingly, increased worry about inconveniencing or offending others by maintaining a strict GFD was associated with poorer adherence, presumably because, under such circumstances people choose to not adhere to the GFD to avoid offending others. Finally, holding the belief that it is *not* difficult to eat a balanced GFD was also associated with lower intentions and poorer adherence. This finding may reflect the necessity of remaining vigilant about the GFD in order to avoid gluten exposure.

Based on the interview responses subjective norms did not appear to be an important consideration when deciding whether to maintain a strict GFD. The most commonly cited source of support was the coeliac society, and most felt that having supportive friends and family was helpful but the lack thereof was not enough to influence the respondents in the direction of non-adherence. This trend was supported by the lack of internal consistency in the direct measures, and the lack of significant correlations between the normative beliefs and adherence. Further, it has been found that the subjective norm component of the TPB represents the weakest predictor of behavioural intentions across a range of health behaviours, including healthy eating (Armitage, & Conner, 2001; Povey, Conner, Sparks, James, & Shepherd, 2000).

The control factors showing significant correlations with intention and adherence reflected primarily internal control factors. For example, knowledge of ingredients and label reading, confidence to ask questions about contamination, and being prepared and organised were all associated with better intention and adherence, consistent with a recent study that assessed the consumption of low-fat foods in people with type II diabetes, and found that the extent of planning surrounding eating low-fat foods mediated the relationship between intention and behaviour (White, Terry, Troup, Rempel, & Norman, 2010).

Having less difficulty trusting non-coeliac individuals to prepare food was associated with poorer intentions and adherence, again presumably because a high level of vigilance is needed to avoid gluten. This finding combined with the previously discussed concern about offending or inconveniencing others, suggests that while worry and trust issues are seen as disadvantages of the diet they are necessary to maintain

strict adherence. External control factors included the availability of GF foods and the clear labeling of products.

Overall, the value of the interview study lies not only in the use of a health model, but the resultant capacity to differentiate between factors perceived to pose challenges to adherence, and the mechanisms through which individuals with CD actually make decisions about their diet. That is, although there are numerous external challenges associated with maintaining a strict GFD, these challenges do not necessarily lead to decreases in adherence, as individuals also possess a large number of internal strengths and coping strategies to overcome these challenges.

The TPB and GFD adherence

The present results consistent with meta-analytic findings that the TPB accounted for 27% of variance in behaviour and 39% of the variance in intention (Armitage & Conner, 2001). The model predicting intention was highly significant, with attitude, PBC, behavioural and normative beliefs contributing. The prediction of adherence from the direct and indirect measures was also highly significant,. A higher perception of control was associated with better adherence; however stronger normative beliefs were associated with poorer adherence. This discrepant finding may suggest that while feeling pressure from others to adhere to the diet is useful in forming a positive intention, in situations when CD individuals are not entirely in control and are somewhat dependent on other people for food preparation (e.g., restaurants, social events) being less susceptible to the perceptions of others is helpful in maintaining diet.

A similar gap between the prediction of intention and behaviour has often been observed, with the TPB accounting for more variance in intention than behaviour

(Amitage, & Conner, 2001). It may be the case that planning represents the factor that allows for the translation of intention into behaviour (Norman, & Conner, 2005; White et al., 2010). In the present case the fact that increased planning was mentioned as part of the PBC construct may indicate that although a positive attitude contributes to the development of intention, when it comes to the behaviour it is the increased perception of control (including planning) that determines how strictly the diet is followed.

Psychiatric diagnoses

There was a high rate of self-reported psychiatric conditions within the sample. In particular depression and poorer QOL were associated with poorer adherence.

Psychiatric history did not predict intention to maintain a strict GFD, perhaps indicating that the presence of psychiatric problems represents a control factor and negatively affects the translation of intention into behaviour. This is important as patients suffering from comorbid depression were found to be three times more likely to be non-compliant with medical treatment recommendations, including several studies of dietary adherence in end stage renal disease (DiMatteo, Lepper, & Croghan, 2000). Similarly, previous research has also found that the *perceived* ability to maintain a GFD despite variations in mood and stress was a significant predictor of actual adherence (Leffler et al., 2008).

Limitations and future directions

This study had several limitations. Firstly, the method of recruitment and low response rate (20%) may have biased the sample towards a more highly adherent population and less representative sample than is typical. That is, members of the coeliac society, and particularly those who chose to respond, may be more invested in

their health and diet than those diagnosed with CD who have chosen not to obtain membership. This same point has been noted in other adherence studies; however, given the nature of the research (online, questionnaire based) alternate options for recruitment were necessarily limited. Secondly, there was a significant gender bias in the responses to the main study (83% female). Women are, however, two-to-three times more likely to be diagnosed with CD, although the reason for this gender imbalance is currently unknown (Green, & Cellier, 2007). In NSW the coeliac society database contains 80% females, indicating that the gender imbalance here is largely consistent with the coeliac society population (personal communication NSW Coeliac Society, 2010).

The use of self-report measures for GFD adherence and psychiatric diagnoses may have produced some measurement error. In the absence of another reliable measure suitable for the online questionnaire-based nature of the present research the CDAT was chosen as the measure of GFD adherence. The simple self-report measure of psychiatric conditions also represents a limitation, and as such the incidence of depression and anxiety may have been overestimated. Finally, the cross sectional design of the study may limit the generalisability of the findings as data was collected at only one time point. It is also impossible to infer any causation between beliefs, adherence and QOL.

Future research could focus on assessing psychological characteristics associated with GFD adherence by employing validated assessment tools designed to measure the presence of affective symptoms in addition to the self-report used here, to determine the impact of such conditions on adherence and the interaction with the rational components of decision making encompassed by the TPB.

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Table 1. Categories of beliefs elicited in the interviews.

| Component | Category | N |
|---------------------|--|----|
| Behavioural beliefs | Minimise symptoms | 11 |
| | Feel physically better | 10 |
| | Increased energy | 6 |
| | Encourages a healthier diet | 9 |
| | Reduced long term health complications | 7 |
| | Difficulties eating away from home (e.g., restaurants, friend's houses, group/ catered events) | 12 |
| | Social restrictions | 8 |
| | Increased planning and preparation | 5 |
| | Not wanting to draw attention to self/ embarrassment | 9 |
| | Increased cost | 5 |
| | Convenience foods | 7 |
| | Travel (remote Australia and overseas) | 7 |
| | Maintaining a nutritionally balanced diet | 4 |
| | Missing out on particular foods | 5 |
| | Worry about inconveniencing/ offending others | 3 |
| | Often focused on food and self | 3 |
| Normative beliefs | Family | 7 |
| | Spouse/ partner | 4 |
| | Friends | 5 |

| | | |
|-----------------|---|----|
| | Work colleagues | 4 |
| | The coeliac society | 8 |
| | Friends and family who also have CD | 5 |
| Control beliefs | Lack of awareness from restaurant staff | 10 |
| | Difficulty trusting others to prepare food | 8 |
| | Availability of naturally GF products | 5 |
| | Supportive friends/ family | 6 |
| | In control of kitchen and food | 5 |
| | Clearly labeled products | 4 |
| | Knowledge of ingredients | 8 |
| | Confidence in asking questions about contamination | 5 |
| | Difficulty in overseas countries (availability and language barriers) | 8 |
| | GF items marked on menus | 5 |
| | Availability of GF foods | 13 |
| | Social/ group events where GF not catered for | 9 |
| | Prepared/ organised | 10 |
| | Lack of awareness from general public | 7 |

Table 2. Items included in the behavioural, normative, and control belief composites

| Component | Item | Correlation with intention | Correlation with adherence |
|------------------------|--|----------------------------------|----------------------------------|
| Behavioural beliefs | 1. Maintaining a strict GFD will prevent/ minimise my CD symptoms | .348** | -.213** |
| | 2. I feel physically better when maintaining a strict GFD | .255** | -.182** |
| | 3. I have more energy when maintaining a strict GFD | .293** | -.172** |
| | 4. Maintaining a strict GFD encourages me to eat a healthy diet (e.g., more natural and fewer refined/processed products) | .206** | -.098 |
| | 5. Maintaining a strict GFD will minimise the risk of me developing long term health complications such as cancer, osteoporosis and infertility | .214** | -.051 |
| | 13. Eating a nutritionally balanced diet is difficult when maintaining a strict GFD (reverse scored) | -.156* | .195** |
| | 15. I worry about inconveniencing or offending other people by maintaining a strict GFD (reverse scored) | .095 | -.230** |
| | Normative | 1. My family... | .149* |

| | | | |
|----------------------|--|--------|---------|
| beliefs ¹ | | | |
| | 2. My spouse/ partner... | .250** | -.031 |
| | 3. My close friends... | .239** | .045 |
| | 4. My work colleagues... | .200** | .048 |
| | 6. The coeliac society... | .177** | .129* |
| | 7. My friends/ family who also have CD... | .138* | .068 |
| | 8. My friends/ family who also have CD maintain a strict GFD | .154* | -.010 |
| Control beliefs | 2. It is difficult to trust people who don't have CD (e.g., friends, family, food staff) to prepare my food (reverse scored) | -.134* | .162* |
| | 5. I am in control of the household food and kitchen | -.118 | .217** |
| | 6. GF products are clearly labeled | .178** | -.237** |
| | 7. I can determine whether a product is safe using my knowledge of ingredients and label reading | .248** | -.255** |
| | 8. I am confident in my ability to safely identify GF foods and to ask the necessary questions about contamination | .297** | -.313** |
| | 11. GF products are readily available (e.g., in supermarkets, food outlets, while traveling or on the road) | .151** | -.216** |
| | 13. I am prepared and organised with regard | .245** | -.175** |

| | | | |
|--|--|--|--|
| | to my diet (e.g., call the restaurant beforehand to enquire about GF options, carry GF food with me, eat before going out) | | |
|--|--|--|--|

1. All subjective norms questions took the form “[Insert referent] think/s I should maintain a strict gluten free diet.”

GFD = gluten free diet

GF = gluten free

CD = coeliac disease

* $p < .05$

** $p < .01$

Table 3. Mean scores on all measures.

| Measure | Mean (SD) | SD | Lower range | Upper range |
|--------------------------|-----------|------|-------------|-------------|
| CDAT | 12.8 | 3.3 | 7 | 26 |
| Intention | 6.7 | 0.7 | 1.3 | 7 |
| Attitude | 5.6 | 0.8 | 1.6 | 7 |
| Subjective norm | 3.0 | 1.6 | 1.0 | 7 |
| PBC | 6.4 | 0.7 | 2.3 | 7 |
| Behavioural beliefs | 11.8 | 2.4 | 4.1 | 19 |
| Normative beliefs | 10.0 | 5.7 | -8.1 | 21 |
| Control beliefs | 13.1 | 3.6 | -3.6 | 19 |
| Physical QOL | 70.1 | 17.9 | 10 | 100 |
| Psychological QOL | 67.1 | 16.5 | 20 | 100 |
| Social QOL | 70.6 | 18.5 | 8 | 100 |
| Environmental QOL | 75.8 | 12.4 | 31 | 100 |
| Overall QOL | 4.21 | 0.9 | 1 | 5 |
| Satisfaction with health | 3.49 | 1.1 | 1 | 5 |
| GF knowledge (% correct) | 80.3 | 11.8 | 57 | 100 |

CDAT: range = 7 – 35; higher scores indicate poorer adherence

Direct measures: range = 1 – 7; higher scores indicate more positive intentions, attitudes, subjective norm, and perceived control

Indirect measures: range = -21 – 21; higher (absolute value) scores indicate stronger belief; positive scores indicate more positive beliefs

WHOQOL domains: range = 0-100; higher scores indicate better QOL

WHOQOL single items: range = 1-5; higher score indicates better QOL

Table 4. Correlations between adherence, TPB variables, QOL, and knowledge

| | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. |
|--------------------|---------|---------|---------|---------|---------|--------|---------|---------|--------|
| 1. CDAT | -.295** | -.263** | .212** | -.472** | -.209** | .059 | -.270** | -.348** | -.070 |
| 2. Intention | 1 | .395** | -.132* | .559** | .352** | .253** | .293** | .027 | .080 |
| 3. Attitude | | 1 | -.161** | .378** | .309** | .153** | .191** | .167* | -.102 |
| 4. Subjective norm | | | 1 | -.247** | -.134* | .276** | -.148* | -.121 | -.078 |
| 5. PBC | | | | 1 | .268** | .161** | .395** | .159* | -.002 |
| 6. Behavioural | | | | | 1 | .132* | .216** | .110 | -.031 |
| 7. Normative | | | | | | 1 | .148* | -.076 | -.059 |
| 8. Control | | | | | | | 1 | .140* | .003 |
| 9. Overall QOL | | | | | | | | 1 | -.140* |
| 10. Knowledge | | | | | | | | | 1 |

Note: CDAT = coeliac dietary adherence test (adherence measure)

PBC = perceived behavioural control

QOL = quality of life

* $p < .05$

** $p < .01$

Table 5. Summary of hierarchical regression analysis predicting intention to maintain a strict GFD

| Variable | B | SE B | β |
|---------------------|-------|------|---------|
| Step 1 | | | |
| Attitude | .168 | .045 | .160** |
| Subjective Norm | .012 | .023 | -.002 |
| PBC | .479 | .056 | .427*** |
| Step 2 | | | |
| Attitude | .127 | .045 | .160** |
| Subjective Norm | -.001 | .025 | -.002 |
| PBC | .415 | .059 | .427*** |
| Behavioural beliefs | .047 | .016 | .156** |
| Normative beliefs | .014 | .007 | .114* |
| Control beliefs | .009 | .011 | .046 |
| Step 3 | | | |
| Attitude | .134 | .045 | .169** |
| Subjective Norm | -.003 | .025 | -.006 |
| PBC | .421 | .059 | .433*** |
| Behavioural beliefs | .048 | .017 | .160** |
| Normative beliefs | .013 | .007 | .109 |
| Control beliefs | .011 | .011 | .057 |
| Depression | -.037 | .081 | -.026 |
| Anxiety | .037 | .082 | .026 |
| Overall QOL | -.068 | .043 | -.088 |

Note: PBC = perceived behavioural control

QOL = quality of life

* $p < .05$

** $p < .01$

*** $p < .001$

Table 6. Summary of hierarchical regression analysis predicting GFD adherence

| Variable | B | SE B | β |
|---------------------|--------|------|----------|
| Step 1 | | | |
| Intention | -1.360 | .288 | -.294*** |
| Step 2 | | | |
| Intention | -.107 | .329 | -.023 |
| Attitude | -.323 | .233 | -.088 |
| Subjective Norm | .176 | .118 | .089 |
| PBC | -1.803 | .323 | -.401*** |
| Step 3 | | | |
| Intention | -.106 | .335 | -.023 |
| Attitude | -.314 | .233 | -.086 |
| Subjective Norm | .036 | .125 | .018 |
| PBC | -1.738 | .330 | -.387*** |
| Behavioural beliefs | -.106 | .085 | -.076 |
| Normative beliefs | .092 | .035 | .163** |
| Control beliefs | -.094 | .056 | -.104 |
| Step 4 | | | |
| Intention | -.275 | .316 | -.060 |
| Attitude | -.175 | .221 | -.048 |
| Subjective Norm | .002 | .118 | .001 |
| PBC | -1.574 | .312 | -.350*** |
| Behavioural beliefs | -.118 | .081 | -.085 |
| Normative beliefs | .073 | .034 | .129* |

| | | | |
|-----------------|--------|------|----------|
| Control beliefs | -0.064 | .053 | -.071 |
| Depression | -1.023 | .389 | -.156** |
| Anxiety | -.522 | .391 | -.080 |
| Overall QOL | -.683 | .207 | -.191*** |

Note: PBC = perceived behavioural control

QOL = quality of life

* $p < .05$

** $p < 01$

*** $p < .001$

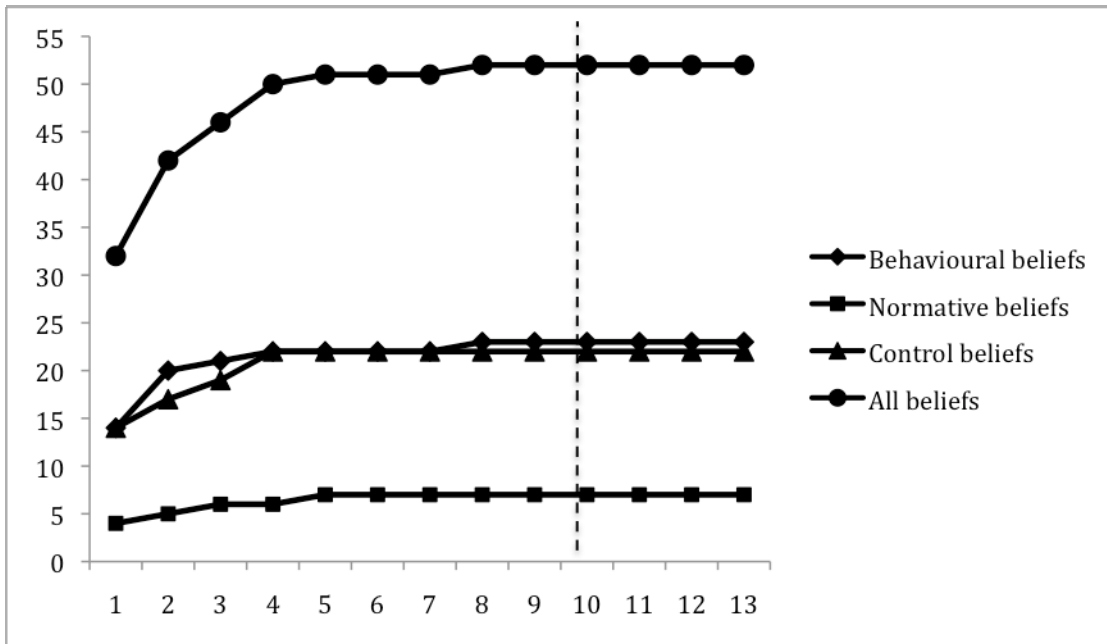


Figure 1. Cumulative frequency graph for behavioural, normative, control, and all beliefs mentioned by participants 1-13.