Maintenance of a gluten free diet in coeliac disease: The roles of self-regulation, habit, psychological resources, motivation, support, and goal priority

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ABSTRACT

Introduction: A strict lifelong gluten free diet (GFD) is the only treatment for coeliac disease (CD). Theory-based research has focused predominantly on initiation, rational, and motivational processes in predicting adherence. The aim of this study was to evaluate an expanded collection of theoretical constructs specifically relevant to the maintenance of behaviour change, in the understanding and prediction of GFD adherence.

Methods: Respondents with CD (N=5573) completed measures of GFD adherence, psychological distress, intentions, self-efficacy, and the maintenance-relevant constructs of self-regulation, habit, temptation and intentional and unintentional lapses (cognitive and behavioural consequences of lowered or fluctuating psychological resources and self-control), motivation, social and environmental support, and goal priority, conflict, and facilitation. Correlations and multiple regression were used to determine their influence on adherence, over and above intention and self-efficacy, and how relationships changed in the presence of distress.

Results: Better adherence was associated with greater self-regulation, habit, self-efficacy, priority, facilitation, and support; and lower psychological distress, conflict, and fewer self-control lapses (e.g., when busy/stressed). Autonomous and wellbeing-based, but not controlled motivations, were related to adherence. In the presence of distress, the influence of self-regulation and intentional lapses on adherence were increased, while temptation and unintentional lapses were decreased.

Discussion: The findings point to the importance of considering intentional, volitional, automatic, and emotional processes in the understanding and prediction of GFD adherence. Behaviour change interventions and psychological support are now needed so that theoretical knowledge can be translated into evidence-based care, including a role for psychologists within the multi-disciplinary treatment team.

KEYWORDS: Gluten free diet adherence; coeliac disease; maintenance; self-regulation; habit; distress; theory

INTRODUCTION

The sole treatment for coeliac disease (CD) is lifelong adherence to a strict gluten free diet (GFD; Hardy & Tye-Din, 2016). Failure to achieve this, even due to trace amounts of gluten, can result in the persistence of gastrointestinal symptoms and place individuals at risk of long-term health complications such as cancer, infertility, and osteoporosis (Green & Jabri, 2003). There is an assumption within the medical and dietetic fields that giving a patient information about their condition and the associated risks, and providing information about its treatment, will be sufficient to prompt good adherence (e.g., Ciacci et al., 2015). The reality of behaviour change is, however, far more complex than the provision of knowledge and instruction alone (Hornik, 1989; Sainsbury, Mullan, & Sharpe, 2013b), and many patients with CD struggle to meet the strict but necessary standards for adherence (Hall, Rubin, & Charnock, 2009).

GFD adherence is the outcome of a series of complex patient behaviours, including the reading of food labels and ingredient lists, ensuring safe food preparation at home, telling the people who are responsible for preparing food about your CD and need for a GFD, and asking questions about food preparation and the risk of contamination when eating away from home, among others. Understanding the modifiable determinants of poor adherence is essential for the design of evidence-based strategies to improve dietary adherence and health. We and others have shown that a range of patient factors including food label-reading skills, degree of symptomatology to gluten exposure (Halmos et al., 2017), and depressive symptoms (Sainsbury & Marques, 2018), are associated with, and likely to influence, both behaviour and dietary adherence, but ultimately patient behaviour is the most important and modifiable determinant. One means to the development of interventions is the use of health behaviour change theory (e.g., Craig et al., 2008). The successful application of theory to a behavioural problem, such as GFD adherence, provides a blueprint or logic model for intervention efforts by suggesting the mechanisms via which changes in behaviour may be achieved (Bartholomew Eldredge et al., 2016; Glanz & Bishop, 2010; Michie & Prestwich, 2010). Theory-based behaviour change interventions are potentially more effective than

1 those without a theoretical basis, and have the advantage of giving insight into why an intervention
2 does or does not work (Glanz & Bishop, 2010; Michie, Johnston, Francis, Hardeman, & Eccles, 2008;
3 Webb, Joseph, Yardley, & Michie, 2010).
4 Few studies have applied theory to the understanding and prediction of GFD adherence in
5 CD, and only one intervention designed specifically to improve adherence has been published
6 (Sainsbury et al., 2013b; Sainsbury, Mullan, & Sharpe, 2015b). Using the theory of planned behaviour
7 (TPB), attitudes and perceived behavioural control (PBC) predicted significant variance in both the
8 intention to follow a strict GFD and GFD adherence (Sainsbury & Mullan, 2011; Sainsbury, Mullan, &
9 Sharpe, 2013a). The presence of an intention-behaviour gap, however, suggested that additional
10 factors are needed to explain why some individuals struggle to remain gluten free despite having
11 strong intentions (Sainsbury et al., 2013a). Extending the TPB, it was found that the interaction
12 between intention, habit, and PBC predicted GFD adherence, such that individuals with both low
13 habit and low PBC had the worst adherence, regardless of their level of intention; whereas for
14 people with high habit and low PBC, adherence did increase as a function of intention (Kothe,
15 Sainsbury, Smith, & Mullan, 2015). It was acknowledged that habit may be a better predictor if
16 applied to the separate behaviours that comprise adherence, as differences in the likelihood and
17 desirability of automaticity for these may differ.
18 Protection motivation theory (PMT) was recently applied to GFD adherence, differentiated
19 based on whether gluten consumption was intentional or accidental (Dowd, Jung, Chen, &
20 Beauchamp, 2016). Intentions (or protection motivation) were a direct predictor of intentional but
21 not unintentional gluten consumption. Additional, indirect predictors (via intention) of intentional
22 consumption were greater symptom severity, lower perceptions of the costs of following a GFD
23 (distress, barriers, and stigma), greater self-regulatory efficacy, more frequent planning, and better
24 knowledge. In contrast, self-regulatory efficacy, or having the confidence to regulate one's
25 behaviour to maintain a strict GFD, was the only predictor of less frequent *unintentional* gluten
26 consumption, and this exerted a direct rather than indirect effect (Dowd et al., 2016).

A similar pattern of results was found by Hall, Rubin, and Charnock (2013), whereby the only correlates of unintentional consumption were related to self-efficacy (perceived difficulty, control, and confidence), whereas intention, attitudes, symptoms (experienced and perceived tolerance), and social support were additionally related to intentional gluten consumption. By definition, unintentional gluten consumption – typically the most common cause of non-adherence (Hall et al., 2013) – happens outside of conscious awareness and is not easily amenable to accurate self-report, as not all individuals with CD are symptomatic upon exposure. Even for those who are symptomatic, the realisation of accidental consumption is a post-hoc one, and although attributed to gluten, other factors (e.g., other intolerances/allergies, stomach bug) may be responsible for the observed reaction. Methodologically, it is therefore not surprising that rational factors, such as those encompassed by most behaviour change theories, are limited in predicting unintentional gluten consumption.

One of the major challenges of behaviour change is the continued maintenance of changes after initial improvements. In a systematic review of over 100 behaviour change theories (Kwasnicka, Dombrowski, White, & Sniehotta, 2016), five maintenance-specific themes were identified. As applied to GFD adherence, maintenance motivation (theme 1) refers to the development of personal reasons to *continue* following a GFD, as once the salience of pre-diagnosis symptoms is reduced, their power as a continued motivator is also likely reduced. GFD adherence is a complex behaviour requiring active self-regulation (theme 2; e.g., reading labels and planning if eating out) for success in both initiation and maintenance phases. With repeated performance over time, these behaviours should become habitual or automatic (theme 3) and require less conscious regulation. Psychological resources (theme 4) refer to internal resources that can be drawn on to prevent lapses in GFD adherence when self-control may be low or fluctuating due to factors such as tiredness, low mood, or stress, or from the effort involved in maintaining adherence itself. Difficulties in assessing such state-based experiences in a cross-sectional design meant that psychological resources were operationalised here as the frequency of cognitive (temptation) and behavioural (intentional and

unintentional gluten consumption) consequences of lowered psychological resources and self-control. Social and environmental influences (theme 5) include the supportiveness of the people and environments in which the GFD is being attempted. These constructs received support in a within-person study of adherence to a weight loss maintenance plan (Kwasnicka, Dombrowski, White, & Sniehotta, 2017), but have not been applied together in other behaviours. Finally, previous research has highlighted the importance of three additional constructs for behavioural maintenance: namely, priority level, and the balancing of unrelated goals that may either facilitate or conflict with goal achievement (Conner et al., 2016; Presseau, Sniehotta, Francis, & Gebhardt, 2010) – for example, the goal of maintaining a strict GFD may sometimes conflict with the goal of being social, whereas the goal of healthy eating may facilitate the GFD. Confidence for this task (concurrent self-regulatory efficacy) is correlated with both GFD adherence and quality of life in patients with CD (Dowd & Jung, 2017).

Given the lifelong necessity of the GFD for patients diagnosed with CD, viewing adherence through the lens of maintenance may advance current understanding beyond that determined using theories of motivation and initiation. Previous theory- and non-theory-based research in CD also supports the relevance of several maintenance constructs. For example, the perceived ability to maintain adherence despite changes in mood and stress (similar to psychological resources) was related to GFD adherence (Leffler et al., 2008); and social (e.g., avoiding social eating, not wanting to draw attention to oneself or inconvenience/burden others, perceived social support) and environmental factors (e.g., travelling and school/work) are often cited as difficulties associated with the GFD (e.g., Hall et al., 2013; Leffler et al., 2008; Sainsbury & Mullan, 2011; Zarkadas et al., 2013). As outlined, the roles of habit (Kothe et al., 2015) and planning (Dowd et al., 2016) have also been supported. Finally, relationships between participant characteristics (e.g., GFD duration), acceptability (e.g., of goal setting and planning tasks, length of intervention), and attrition following participation in a successful TPB-based intervention provide indirect support for their relevance (Sainsbury, Mullan, & Sharpe, 2015a).

The aims of this study were to firstly understand whether, and how, the ten aforementioned maintenance constructs could be used to advance understanding of GFD adherence; and secondly, to determine the contribution of these constructs to predicting GFD adherence, over and above the well-supported variables of intention and self-efficacy (Kothe et al., 2015; Sainsbury & Mullan, 2011; Sainsbury et al., 2013a). Depressive symptoms, which have a moderate association with GFD adherence (Sainsbury & Marques, 2018) and partially explained the failure to translate intentions into behaviour (Sainsbury et al., 2013a), were also included. It was hypothesised that each of the ten maintenance constructs would be associated with GFD adherence – that is, better adherence would be related to: (1) more frequent self-regulation, (2) stronger habits, (3) stronger maintenance motivation (particularly autonomous and future-oriented motivations), (4-6) less frequent temptation and intentional and unintentional gluten consumption in circumstances when psychological resources and self-control are low, (7) better social and environmental support, (8-10) higher goal priority and facilitation, and less goal conflict. Consistent with previous studies, it was anticipated that stronger intentions, higher PBC, and lower levels of psychological distress would be associated with better GFD adherence, although the maintenance constructs would add to the prediction of adherence beyond that accounted for by these variables. It was also expected that more frequent self-regulation and a longer time since diagnosis would be associated with stronger habits; higher levels of psychological distress and lower PBC would each be associated with more frequent temptation and un/intentional gluten consumption; and lower priority and higher goal conflict would be associated with both lower maintenance motivation and intention.

METHOD

Participants and recruitment

This was part of a wider study designed to investigate the patient-relevant factors (e.g., demographic, disease, knowledge, psychological) associated with adherence to a GFD (Halmos et al., 2017). The inclusion criteria were that participants needed to be aged ≥13 years and have a biopsy-confirmed diagnosis of CD (self-reported for the purposes of inclusion). Here, only those ≥16 years

were included, as several measures had not been validated in non-adult samples. Recruitment took place in February and March 2017, and involved: email advertisements disseminated by Coeliac Australia and Coeliac New Zealand to their members and at state-based gluten free expos; adverts posted and shared on social media (Facebook pages of state CD organisations and general CD support groups); and word of mouth. Ethical approval was granted by the Melbourne Health Human Research Ethics Committee (LNR/16/MH/169).

Materials and procedure

Interested participants clicked a web-link in the email/advertisement and were directed to SurveyMonkey (SurveyMonkey Inc., 2016) to read a participant information statement and complete the screening questions before accessing the online survey. Eligible participants provided informed consent and were told that they could stop answering the survey at any time. Questions elicited information about a range of demographic (i.e., age, gender, education, ethnicity), diagnostic (e.g., year of diagnosis, reason for diagnosis), and illness variables (e.g., symptoms; see Halmos et al., 2017 for conference abstract; full text in preparation), and the target variables of interest for the theoretical analysis of maintenance. A copy of the questionnaire can be found in the online supplementary material.

GFD adherence: the Coeliac Dietary Adherence Test (CDAT) is a 7-item self-report questionnaire that has good psychometric properties and correlates highly with the 'gold standard' adherence measure, a dietitian-rated assessment (Leffler et al., 2009). Each item is rated on a 5-point Likert scale; responses are summed to provide a total score (range = 7-35); and higher scores indicate poorer adherence (7-12 = excellent or very good adherence; 13-17 = moderate; 18-35 = fair-to-poor).

Intention and PBC: two subscales from the Theory of Planned Behaviour in Coeliac Disease questionnaire, which have acceptable internal consistency (intention: α = .68; PBC: α = .81) (Sainsbury & Mullan, 2011), were used. One additional item measured confidence to maintain a strict GFD in the presence of unexpected barriers and was added to the original scale for scoring

purposes. Each item is rated on a 7-point Likert scale; the total score for each construct represents the average of relevant items (range = 1-7); higher scores indicate stronger intentions and higher confidence, respectively.

Psychological distress: the Kessler Psychological Distress Scale (K-10) was used to measure depression and anxiety, over the past 4 weeks (Kessler et al., 2002). The scale includes 10 items, each measured on a 5-point Likert scale assessing the frequency of symptoms; the total score represents the sum of all items (range = 10-50); and higher scores indicate greater distress (10-19 = well; 20-24 = mild mental disorder; 25-29 = moderate mental disorder; 30-50 = severe mental disorder). Items in the K-10 were derived from those included in 18 previous measures of depression, anxiety, and general distress, and narrowed down following expert consensus and pilot testing. The resultant 10-item scale has undergone rigorous psychometric testing, including further pilot testing via telephone administrations and face-to-face interviews, validation against the Structured Clinical Interview for DSM-IV (SCID), and inclusion in large government health surveys in the USA and Australia. Results showed that the scale has excellent precision and discriminates reliably between cases and non-cases, across a range of sociodemographic characteristics (Kessler et al., 2002).

Maintenance constructs: novel scales were used to measure each of the maintenance-relevant constructs (except habit). A draft version of the maintenance questionnaire was reviewed by members of the health psychology group at the Institute of Health and Society, Newcastle University, for coverage of the relevant constructs. Prior to recruitment, the newly-developed questionnaire (maintenance constructs plus the CD history and dietetic questions) was also piloted in a face-to-face group setting with eight adult members of Coeliac Victoria, and separately with two members of Coeliac NSW. After completing the questionnaire individually, the volunteers discussed any items (content and/or wording) that concerned them and notes were passed onto the research team. In addition, the questionnaire was reviewed by the multi-disciplinary study team (gastroenterologist, dietitian, and three psychologists), two additional practicing dietitians, and

research staff members at the Walter and Eliza Hall Institute who were not involved in the study (two research nurses, post-doc, research assistant). Changes to the wording and content of questions were then made, as appropriate. A copy of the full questionnaire can be found in the online supplementary material.

Habit: a single item ('X is something I do automatically') from the Self-Report Habit Index (SRHI; Gardner, Abraham, Lally, & de Bruijn, 2012; Verplanken & Orbell, 2003) was used to measure the level of automaticity of each component behaviour involved in achieving GFD adherence, rather than the complex behaviour of adherence as a whole (as suggested by Kothe et al., 2015): (1) reading ingredients lists and nutritional labels and 'may contain' statements to identify gluten containing ingredients; (2) taking measures to avoid cross-contamination when preparing food at home; (3) asking questions about food preparation and the risk of cross-contamination when eating away from home; (4) telling the person who is cooking/preparing food about your CD and need for a strict GFD; (5) planning ahead when eating away from home; and (6) having gluten free foods on hand in case of a lack of availability when away from home. Responses were given on a 7-point Likert scale with higher scores reflecting more habitual behaviour. Component behaviours were informed by those included in the Biagi GFD score (Biagi et al., 2009) and examples elicited in an interview study (Sainsbury & Mullan, 2011). Choice of this item from the 12-item SRHI was informed by data showing that it best captured the construct of automaticity and was well-understood by participants (B. Gardner, personal communication, November 17, 2016).

Self-regulation: six items referred to the above component behaviours, reflecting the frequency with which each was performed to ensure strict adherence to the GFD (rated on a 5-point Likert scale: never-always; recoded to 7-points so the mean was comparable to habit). One additional item, adapted from the Action and Coping Planning Scales (Sniehotta, Schwarzer, Scholz, & Schuz, 2005), measured coping planning (i.e., having a plan for how to maintain strict GFD adherence in the presence of unexpected barriers; rated on a 7-point Likert scale) and was combined with the component behaviour items for the purposes of scoring.

Psychological resources: operationalised as the cognitive and behavioural consequences of lowered or fluctuating self-control, participants indicated the frequency of (1) temptation to break their GFD, and (2) intentional and (3) unintentional gluten consumption, under 11 conditions when the availability of psychological resources is likely to be reduced: tired, busy/limited time, break in usual routine, bored, stressed, upset/down, emotionally exhausted, low energy, unmotivated, physically unwell, and unable to see any positive effect of the GFD. Due to the difficulty of measuring unintentional gluten consumption directly (as, by definition, it happens outside of present-moment awareness), this was inferred from the frequency of "being less careful or paying less attention to your diet, being less likely to plan in advance, or taking more risks with label reading or other measures you would typically use to avoid gluten." The specific conditions were informed by a measure of the frequency of depletion experiences, used in a weight loss maintenance trial (Evans et al., 2015). Each item was measured on a 5-point Likert scale (never-always), with higher scores indicating more frequent temptation and consumption. Although intentional and unintentional gluten consumption reflect patient behaviours and therefore overlap to some extent with the measure of GFD adherence, an important difference is that the CDAT score reflects the *outcome* of a series of complex behaviours, rather than behaviour per se. Further, by linking un/intentional gluten consumption specifically to the experience of conditions in which psychological resources and self-control are likely to be lowered, this construct can be differentiated from self-regulation, which simply reflects frequency of performance of the component behaviours.

Social and environmental support: participants indicated the practical and emotional support received in relation to maintaining a strict GFD and, if there was somebody close to them (e.g., family member) with CD, they also indicated practical and emotional support from those people. Three items measured the supportiveness of the home, work/study, and weekend environments. Choice of these domains was based on the division into practical and emotional support in existing social support scales (e.g., Mitchell et al., 2003), and evidence for the relevance of different environments (e.g., home, work, and socialising/eating out which are likely to happen

more on weekends) in previous GFD research (e.g., Leffler et al., 2008; Sainsbury & Mullan, 2011). Each item was measured on a 0-100-point sliding scale (not at all-completely).

Maintenance motivation: 15 items measured reasons for continuing to follow a GFD on a day-to-day basis (which may be different to what motivated the initiation of a GFD in the first place). The specific reasons were drawn from the attitude items of the Theory of Planned Behaviour-Coeliac Disease questionnaire (e.g., to avoid symptoms and long-term health complications, to feel physically and emotionally well; Sainsbury & Mullan, 2011); and autonomous (e.g., following a GFD has become part of who I am/is consistent with other things that matter to me) and controlled motivation items (e.g., I would feel guilty if I did not follow a GFD; other people expect me to) from self-determination theory, as previously applied in a weight loss context (Pelletier, Dion, Slovinec-D'Angelo, & Reid, 2004). The latter also overlap with the subjective norm items from the TPB (Sainsbury & Mullan, 2011). All items were answered using a 0-100-point sliding scale (not at all-completely).

Goal priority, goal conflict, goal facilitation: single-items, rated on a 7-point Likert scale (strongly disagree-strongly agree), were used for each construct. For goal priority (reverse-scored) and facilitation, higher scores indicated greater priority and facilitation, whereas a higher conflict score indicated that more got in the way of the GFD. Items were adapted from a series of studies on the impact of goal priority and conflict on the intention-behaviour gap, for which some single items were used (Conner et al., 2016). Question framing was different here as the behaviour of GFD adherence is not time-bound (i.e., needs to be performed for life). Conflict and facilitation were asked about separately based on evidence that they are not merely two ends of the same continuum (Presseau et al., 2010).

Data analysis

Time since diagnosis was computed by subtracting the year of diagnosis from 2017; age at diagnosis was computed by subtracting this value from current age. Raw data from validated questionnaires were combined to produce one score per construct (i.e., GFD adherence,

psychological distress, intention, PBC). Due to positive skews on both time since diagnosis (towards more recent; skewness = 1.97, kurtosis = 6.00) and GFD adherence (towards better adherence; skewness = 0.89, kurtosis = 1.04), natural log transformations were applied to create distributions that approached normality (time: -0.39, -0.64; adherence: 0.18, -0.33). Untransformed values were used for descriptive purposes and transformed for inferential statistics. Differences in GFD adherence and psychological distress, by gender, were assessed using independent samples *t*-tests.

Descriptive statistics (% or mean and standard deviation; SD) were computed for each maintenance item. For each of self-regulation, habit, psychological resources (temptation and un/intentional gluten lapses), social and environmental support, and maintenance motivation, a factor analysis using the principal components extraction method and promax rotation was conducted to determine the number of components emerging from the data (based on eigenvalues $\geq$1). An oblique rather than orthogonal rotation was chosen as it was expected that items within each construct (and therefore any extracted components) would be correlated with each other. Subscale scores represented the average of relevant items; Cronbach's alphas indicated internal consistency.

Spearman's correlations were conducted to determine the bivariate relationships between GFD adherence, time since diagnosis, and the ten maintenance constructs (individual items and subscale scores). A hierarchical multiple regression analysis was used to determine the variance accounted for by the maintenance constructs and their unique role in predicting GFD adherence. At step 1, intention and PBC were entered to confirm the predictive capacity of the TPB for GFD adherence. At step 2, the 10 maintenance-relevant constructs were entered, followed by psychological distress at step 3 to examine the ways in which the theoretical relationships changed when depression was accounted for.

Given the large sample, effect sizes and 95% confidence intervals rather than *p* values were used to indicate significance. For correlations, the coefficient represented the effect size; for *t*-tests, means and SD were used to compute the effect size (Cohen's d), which were interpreted according

to Cohen's guidelines (r of 0.1/0.3/0.5 indicate small/medium/large effects, respectively; d of 0.2/0.5/0.8 indicate small/medium/large effects respectively; Cohen, 1988).

RESULTS

Response rate

A total of 7393 people accessed the online survey and 7227 consented to participate. Of these, 7044 had CD (95.3%) and provided some information. A small group were unsure about their diagnosis (n = 114) or answered 'no' to this question (n = 69), with all such participants being excluded from analysis. To be included, respondents needed to have a diagnosis of CD, be ≥16 years of age, completed the primary outcome measure (GFD adherence), and provided data for at least one of the theoretical constructs (n = 5773; 78% of those who accessed the survey). Most participants heard about the survey via Coeliac Australia or Coeliac New Zealand (65.9%), followed by social media (27.6%), word of mouth (2.2%), their gastroenterology clinic or healthcare professional (1.8%), a newspaper article (1.8%), a state-based Gluten Free Expo (0.1%), or other (0.5%).

Sample characteristics

The final sample (n = 5773) was predominantly female (83.2%), married or partnered (78.7%), and had a mean age of 50.2 years (SD = 15.9, range = 16-94). Most were currently living in Australia (84.9%; New Zealand: 14.3%; other: 0.8%) and identified as Caucasian (96.1%; the remainder identified as Asian, Aboriginal, Pacific Islander, Maori, or other). The sample was well-educated, with half having completed undergraduate (28.7%) or post-graduate qualifications (21.1%) and a further 21.6% having completed a TAFE certificate (secondary schooling: 16.9%; less than secondary education: 11.6%; missing: 1.1%).

Respondents had been diagnosed with CD between 0 and 71 years ago (M = 10.3, SD = 9.4; n = 120 confirmed their diagnosis but did not provide a date), at the age of between 0 and 84 years (M = 39.7, SD = 15.6). The mean GFD adherence score (M = 12.1, SD = 3.3, range = 7-29) fell in the excellent or very good range, as did the scores of 60.5% of the sample; 33% were classified as having

moderate adherence, and 6.5% had fair-to-poor adherence. The difference in adherence between men (M = 11.3, SD = 3.1) and women (M = 12.3, SD = 3.3) equated to a small effect size (d = .31). Scores for intention (M = 6.4, SD = 1.4) and PBC (M = 6.5, SD = 0.7) were both high. Based on their psychological distress scores (M = 17.2, SD = 6.7, range = 10-50), 71.7% of the sample were classified as being well, 14.4% fell into the mild mental disorder category, 7.2% moderate, and 6.6% severe. The mean distress score for men (M = 15.4, SD = 5.9) and women (M = 17.5, SD = 6.8) placed them in the well category, and the difference between them was small (d = .33).

Scale properties

Factor analyses on each of the multi-item maintenance scales indicated that items loaded on one factor per construct, except for maintenance motivation, which formed four subscales (described separately). Total scores were therefore computed from the average of relevant items, and all had acceptable internal consistency (except one of the motivation subscales). Descriptive statistics and scale properties including reliability, eigenvalues, and the amount of variance accounted for by the first component for each of the maintenance scales are shown in Table 1 (note: goal priority, conflict, and facilitation were assessed using single items and so were not subject to factor analysis).

Table 1. Summary of scale properties

	Mean (SD)	Range	Cronbach's alpha	Eigenvalue	% of variance
Self-regulation	6.0 (0.9)	1-7	.78	3.1	45
Habit	6.0 (1.0)	1-7	.85	3.5	58
Temptation	1.4 (0.7)	1-5	.96	7.8	71
Intentional	1.1 (0.4)	1-5	.96	8.1	74
Unintentional	1.3 (0.6)	1-5	.95	7.7	70
Support	81.5 (19.1)	0-100	.85	3.3	66
Motivation: wellbeing	74.7 (19.9)	0-100	.81	5.0	33
Motivation: symptoms	81.1 (20.3)	0-100	.77	1.7	12
Motivation: controlled	59.5 (25.7)	0-100	.55	1.2	8
Motivation: long-term health*	93.3 (13.7)	0-100	NA	1.0	7
Goal priority*	6.1 (1.4)	1-7	NA	NA	NA
Goal conflict*	1.9 (1.4)	1-7	NA	NA	NA

Goal facilitation*	4.3 (2.0)	1-7	NA	NA	NA

Temptation, intentional, and unintentional all refer to the frequency of cognitive or behavioural lapses when psychological resources and self-control may be low (e.g., when tired, stressed); support refers to both social (practical and emotional) and environmental support (home, work/study, weekend); eigenvalues and % variance based on factor analysis with principal components extraction method and promax rotation; * single-item component/scale

Maintenance motivation

Avoidance of long-term health problems was the strongest motivator for following a strict GFD on a day-to-day basis (see Supplementary Table 1). This was followed by wanting to feel physically well, GFD is 'part of who I am', and symptom avoidance (both since following a GFD and prior to diagnosis). 'Because other people expect me to' was the least motivating factor. Promax rotation identified 4 components with eigenvalues over 1, which together accounted for 59.3% of the variance. The first component, labelled 'wellbeing', consisted of items reflecting autonomous motivations (i.e., satisfaction, enjoyment, consistency with identity and values) and wellbeing (e.g., energy, emotional wellbeing, healthy diet). The second component contained motivations related predominantly to symptoms (e.g., avoiding symptoms experienced pre- and post-diagnosis, feeling physically well). There was some overlap, with increased energy, emotional wellbeing, and being able to achieve more loading on both components 1 and 2. Component 3 contained the three controlled motivations, and component 4 contained the single item relating to avoidance of long-term health problems. For the purposes of computing subscale scores, items with cross-loadings only contributed to the component for which they had the highest loading.

Self-regulation and habit

Reading ingredient lists and 'may contain' statements was the most frequently used self-regulatory behaviour, followed by communicating with people involved in food preparation about CD and the need for a GFD, both of which were used 'always' or 'often' by more than 92% of the sample (see supplementary Table 2). For label reading, the level of automaticity was also high; whereas, although frequently used, communication was not automatic for as many people. Asking

questions about food preparation and cross-contamination was the least frequently used and automatic behaviour. Coping planning was used less frequently than other self-regulatory behaviours, with 71.6% of the sample either agreeing or strongly agreeing that they had a plan for how to maintain a GFD even when unexpected things got in the way.

Psychological resources

Between 68 and 81% of the sample reported that they 'never' felt tempted to break their GFD under each of the 11 circumstances in which psychological resources and self-control may be low; less than 2% said they 'always' felt tempted (see Supplementary Table 3). Intentional gluten consumption was rare under any circumstances (88-94% never), with a maximum of 1.5% endorsing 'always' or 'often'. Being less careful with the GFD was more common than intentional gluten consumption across all circumstances (70-89% never). Being physically unwell, not being able to see any positive effect of the GFD, and feeling bored were the circumstances *least* likely to elicit temptation and consumption. Being busy/having limited time and a break in the usual routine were the circumstances in which people were *most* likely to report temptation and consumption.

Social and environmental support

The mean scores for practical and emotional support were reasonably high (see Supplementary Table 4); the difference between practical and emotional support equated to a small effect size (d = 0.22). Roughly half the sample (47.5%) knew somebody with CD. The mean score for practical support from others with CD was slightly lower than the general practical support received (d = .21). The emotional support received from other people with CD was comparable to general emotional support (d = 0.14). The mean score for a supportive home environment was high and more supportive than the work/study (d = 0.73) or weekend environment (d = 0.40). The weekend environment was more supportive than the work/study environment (d = 0.50).

Goal priority, and conflict vs. facilitation

Most respondents (79.6%) strongly disagreed or disagreed that other activities and goals were a higher priority than maintaining a strict GFD. Only 3.8% strongly agreed or agreed to its lower

priority. Most (80.3%) also reported that other priorities, activities, and goals did not get in the way of them maintaining a strict GFD. Scores for goal facilitation were more varied: 25.3% neither agreed nor disagreed that other priorities, activities, and goals helped them to maintain a strict GFD, 36.2% agreed or strongly agreed, and 24.4% disagreed or strongly disagreed.

Relationships between the maintenance-relevant constructs

All 13 of the resulting maintenance scales (the original ten constructs, including motivation which was split into four subscales) were correlated with GFD adherence in the expected directions (medium effect sizes, except goal facilitation: small, and controlled motivation: trivial; see Supplementary Table 5). All bivariate correlations between these variables were as expected, such that better self-regulation and stronger habits, more support, higher priority and motivation (wellbeing, symptoms, long-term health), fewer barriers, and more facilitators were all related to experiencing less frequent temptation and being less likely to intentionally or unintentionally consume gluten when psychological resources and self-control were low (medium-to-large effects, except goal facilitation: trivial or small). Controlled motivation was only associated with the wellbeing- and symptom-based motivation subscales.

Higher psychological distress scores were significantly correlated with poorer GFD adherence (large effect size), and with *lower* intentions, PBC, habit, support, wellbeing-based motivation, goal priority, and facilitation; and *more* temptation, intentional and unintentional consumption, and goal conflict. The largest associations were with support and temptation (medium effects), PBC, unintentional consumption, and goal conflict (small-to-medium). The correlations with time since diagnosis were trivial-to-small, although generally in the direction of a more favourable profile being associated with longer time since diagnosis.

Predicting GFD adherence

At step 1, intention, and PBC accounted for 17.7% of the variance in GFD adherence. PBC had a medium-to-large effect on adherence, while the effect of intention was trivial (see Table 2). At step 2, the 13 maintenance-relevant variables accounted for an extra 12.3% of the variance (total

30%). The unique effect of most was only small, with social support, temptation, and PBC having the strongest effects. At step 3, psychological distress added a further 13.2% to the model and was the strongest predictor of adherence (medium-to-large effect). Here, the influences of several variables were considerably weakened (e.g., temptation and social support). In contrast, the influences of self-regulation and intentional gluten consumption were strengthened. The strongest predictors after distress were self-regulation, intentional gluten consumption, and PBC, all of which had equivalent, small magnitude effects. The total variance accounted for in the final model was 43.2%.

Table 2. Summary of hierarchical regression analyses predicting GFD adherence

	B	*95% CI (B)*	β	R^2 (Δ)	*F*
Step 1					
Intention	.000	-.004, .005	.002		
PBC	-.151	-.160, -.142	-.421	.177	594.47
Step 2					
Intention	.004	.000, .008	.022		
PBC	-.046	-.057, -.035	-.128		
Self-regulation	-.013	-.023, -.003	-.046		
Habit	-.008	-.017, .002	-.029		
Motivation: wellbeing	-.001	-.001, .000	-.060		
Motivation: symptoms	.001	.000, .001	.045		
Motivation: controlled	.000	.000, .000	-.011		
Motivation: LT health	-.001	-.002, -.001	-.064		
Temptation	.050	.039, .061	.141		
Intentional	.049	.029, .070	.076		
Unintentional	.016	.001, .032	.035		
Support	-.003	-.003, -.002	-.184		
Goal priority	-.003	-.007, .002	-.014		
Goal conflict	.013	.008, .018	.069		
Goal facilitation	-.003	-.006, .000	-.026	.300 (.123)	157.87
Step 3					
Intention	.002	-.002, .006	.009		
PBC	-.037	-.047, -.028	-.104		
Self-regulation	-.030	-.039, -.021	-.109		
Habit	-.003	-.012, .005	-.013		
Motivation: wellbeing	.000	-.001, .000	-.028		
Motivation: symptoms	.000	.000, .000	.009		
Motivation: controlled	.000	.000, .000	-.025		
Motivation: LT health	-.001	-.002, -.001	-.058		
Temptation	.014	.004, .024	.039		
Intentional	.068	.049, .086	.104		
Unintentional	-.009	-.023, .005	-.019		
Support	-.001	-.001, -.001	-.081		
Goal priority	-.003	-.007, .002	-.014		
Goal conflict	.011	.006, .016	.060		
Goal facilitation	-.001	-.004, .002	-.007		
Psych. distress	.017	.016, .017	.418	.432 (.132)	262.24

Note: PBC = perceived behavioural control; based on n = 5542 who had a complete dataset; outcome (CDAT with natural log transformation): higher scores indicate poorer adherence.

DISCUSSION

The GFD is the only way to manage CD, and must be strictly maintained for life after diagnosis (Green & Cellier, 2007). Despite the optimistic disease trajectory if this is achieved, many patients struggle with their adherence (Hall et al., 2009). Current clinical care of patients with CD tends to focus on patient knowledge and practice of the GFD, and there is scant regard for the roles of patient behaviour and the attitudes that shape adherence to the GFD (e.g., Ciacci et al., 2015). By understanding these psychological aspects, it may be possible to develop clinically-relevant approaches that can be applied to support patients to maintain long-term adherence. The primary aim of this study was to determine the fit of a collection of maintenance-specific theoretical constructs (Conner et al., 2016; Kwasnicka et al., 2016; Presseau et al., 2010) to the understanding and prediction of GFD adherence, over and above the known influences of intention and PBC (Kothe et al., 2015; Sainsbury & Mullan, 2011; Sainsbury et al., 2013a), and in combination with depressive symptoms, which are also associated with poorer adherence (Sainsbury & Marques, 2018). The recruitment of more than 5500 individuals with CD allowed for precise estimates of the constructs and the relationships between them, and all hypotheses were supported.

Strength of motivation/intention has been associated with GFD adherence in several studies (Dowd et al., 2016; Hall et al., 2013; Sainsbury & Mullan, 2011; Sainsbury et al., 2013a), although its influence is typically diminished when other variables are accounted for, reflecting the premise that motivation is a necessary but not sufficient condition for behaviour. In a conference abstract (otherwise unpublished), greater autonomous motivation was associated with better GFD adherence (Weiss et al., 2013), but little more is known about the specific types of motivation related to adherence in this population. Although the primary reason for following a GFD in people with CD will be their diagnosis (Dowd et al., 2016), over time, the development of intrinsic reasons for adherence are likely to be associated with better adherence and wellbeing (Ng et al., 2012; Ryan & Deci, 2000). Consistent with this, autonomous (i.e., satisfaction/enjoyment of behaviour and consistency with values) and wellbeing-based motivations (i.e., satisfaction with outcomes, including

reduced symptoms) were most strongly associated with GFD adherence. In line with previous work showing that subjective norms were not relevant in CD (Sainsbury & Mullan, 2011), 'because other people expect me to' had the lowest mean score and controlled motivations were unrelated to adherence.

Most people engaged in label reading and told the person who was preparing their food about their CD and need for a GFD, the former being more automatic than the latter. The discrepancy in automaticity between the two behaviours may reflect the fact that, if the same, limited number of people (e.g., family members and close friends) are responsible for food preparation in most situations, this behaviour would not be required on every eating occasion. In contrast, it is recommended by Coeliac Australia that even frequently-consumed foods and ingredients are checked every time, as manufacturers may have altered their ingredients or production methods, rendering a previously safe product no longer suitable. Forward-planning, coping planning, and having gluten free food on hand in case of lack of availability were used by roughly three-quarters of the sample. While probably making living with CD easier, failure to perform these behaviours on some occasions would not necessarily result in lapses in adherence like not reading labels would. Of some concern, only two-thirds of the sample asked questions about food preparation and cross-contamination risks when eating away from home, and this was the least automatic of the behaviours that comprise adherence. When combined with the observed relationships between more frequent self-regulation and better adherence, this suggests that some people with CD are placing themselves at risk by not engaging in behaviours that are needed to protect their health.

The magnitude of the habit-adherence correlation and the non-unique influence of habit when controlling for other variables was comparable with the previous study (Kothe et al., 2015). Differences in the level of automaticity of each component behaviour, however, supports the decision to assess these separately, and suggests that while some aspects of the GFD are prone to becoming habitual, others may continue to require conscious regulation, even with repeated

performance over time. The former tended to reflect individually-controlled behaviours compared to more complex behaviours with a social or communication element, which have previously been identified as factors that can impede adherence (e.g., Sainsbury & Mullan, 2011). A similar pattern was observed within the social and environmental data, with the home environment being more supportive than either the work/study or weekend environments, where presumably the influence of other people on the ability to maintain strict adherence is greater. The cues in the home environment are also probably more stable than those away from home, which is an important aspect of habit formation. This is consistent with previous research showing that being in control of the household food and kitchen, and comfort following the GFD at work, were associated with better adherence (Leffler et al., 2008; Sainsbury & Mullan, 2011). All social and environmental support items were related to GFD adherence, and the total support score represented the strongest relationship across the univariate and multivariate analyses. Thus, while patient behaviour remains key in adherence, context also needs to be considered.

While motivation/intention were high and self-regulation frequent, there were circumstances related to the depletion of psychological resources in which participants felt tempted to break their diets. Conceptually, these fell into three main categories, although all items loaded on one component. The circumstances in which temptation, and indeed both intentional and unintentional gluten consumption, were *most* likely were practical in nature – that is, being busy or having limited time and having a break from their usual routine. As inferred above, this may reflect the importance of the interaction between environmental factors, such as the ease of finding gluten free foods when eating away from home, and the capacity for self-control depending on the availability of psychological resources. Factors of a physical or internal drive-related nature (i.e., no positive effect of the GFD, physically unwell, tired, lacking energy, bored, unmotivated) were *least* likely to be associated with temptation and consumption. Emotional factors (i.e., stress, upset or down, emotionally exhausted) fell in the middle of practical and physical factors regarding the frequency of eliciting temptation.

Intentional consumption of gluten was uncommon under any circumstances, which is consistent with previous evidence (Dowd et al., 2016; Hall et al., 2013). Direct self-report of unintentional gluten consumption is problematic and previous research has failed to identify predictors comparable to intentional consumption (Dowd et al., 2016; Hall et al., 2013). Here, the frequency of behavioural lapses when psychological resources and self-control were likely to be low was used as a proxy for unintentional gluten consumption. All items and the subscale score were moderately correlated with poorer GFD adherence and strongly associated with PBC. Again, while lapses in self-regulation will not guarantee the ingestion of gluten, if occurring with any regularity, they will certainly place the individual at risk over the longer-term, and therefore represent important targets for intervention. Finally, as predicted, placing a higher priority on the GFD compared to other goals and activities, and experiencing less goal conflict and more facilitation, were related to better adherence.

The predictive capacity of intention and PBC in the multivariate analysis was comparable to previous research, with PBC again exerting a stronger impact than intention (Kothe et al., 2015; Sainsbury & Mullan, 2011; Sainsbury et al., 2013a). As expected, the maintenance constructs added variance and the total was considerably higher than previous predictive models (Kothe et al., 2015; Sainsbury & Mullan, 2011; Sainsbury et al., 2013a). Constructs for which the confidence interval did not include zero were support, PBC, all three components of psychological resources (temptation, and un/intentional gluten consumption), goal conflict, and self-regulation, although the unique influence of the latter four were trivial.

Depressive symptoms show a moderate association with GFD adherence (Sainsbury & Marques, 2018), but the nature of this relationship has not been confirmed. More interesting, therefore, was the change in pattern of predictors when psychological distress (the strongest predictor) was added in the final step. Here, the previously trivial influence of self-regulation was strengthened, suggesting that in the presence of distress, more active self-regulation is needed to ensure good adherence. Additionally, the influence of temptation was reduced, while intentional

gluten consumption in the context of reduced psychological resources became an important predictor of worse adherence. Combined, this suggests that most temptation and consequent lapses in self-regulation when depleted (i.e., unintentional consumption) are accounted for by feeling distressed – that is, depression appears to undermine otherwise good self-regulation and reliance on gluten-avoidance habits, resulting in some people being less vigilant with their diets.

In contrast, intentional gluten consumption in these same circumstances exerted a strong influence on adherence even when distress was accounted for, suggesting that lowered psychological resources also impact adherence via temporary dips in the intention and ability to adhere, regardless of the level of psychological distress. Emotional eating (as prompted by depression, boredom, and anger/anxiety, but not specifically in relation to the consumption of gluten) was previously assessed and was not related to GFD adherence, while the increased use of adaptive, and decreased use of maladaptive, emotion regulation strategies was related to both poorer GFD adherence and increased depression (Kerswell & Strodl, 2015). Thus, it appears that the combination of lowered resources and the ability to effectively regulate behaviour *and* emotions in these circumstances is key in determining their impact on adherence. The still significant influences of PBC and support (albeit reduced) suggest that these factors may be protective in the presence of distress. These findings extend previous work (Sainsbury & Marques, 2018) by suggesting specific means via which depression may impact the intention-behaviour gap.

The main limitation of this study was the cross-sectional design, which means that causation between the various theoretical constructs, and with adherence, cannot be established. Future research using prospective or longitudinal designs would help to elucidate how these factors influence each other and vary over time. Nonetheless, the very large sample size is a strength, which resulted in greater precision of measurement than has been possible in most previous studies, where sample sizes were typically in the range of 200-500. The large sample also somewhat outweighs the potential biases associated with recruitment via CD support groups, active members of whom may not be representative of the wider CD population. The imbalance towards more

recent diagnosis may suggest that established patients are less likely to be in contact with such support, although arguably, it is the newer group of patients who may be more in need of support with their adherence. Recruitment through official (Coeliac Australia/New Zealand and state organisations) and unofficial (Facebook groups) disease-specific support networks was undertaken to increase reach within the target population to include non-members of the Coeliac Society. The observation that these were the main sources of access to the survey, however, means that people from outside any organised networks were under-represented in the sample, posing a potential threat to generalisability.

There was a strong gender bias (83% female) over and above the established biological imbalance that exists in CD and other autoimmune conditions (Green et al., 2001), and the majority of the sample were Caucasian (96%). In a serogenetic screening study conducted in representative community cohorts of men and women in Australia, estimates of CD were considerably higher in women (1.9%) than men (1.2%) (Anderson et al., 2013). The sample on which these estimates are based mirrors the national Australian population by socioeconomic status, education, country of birth (only 2.3% were born in countries that are not predominantly Caucasian), and age breakdown (Anderson et al., 2013; Pasco, Nicholson, & Kotowicz, 2011). Thus, compared to recent estimates, the current sample is reasonably representative of the population of people diagnosed with CD in Australia, as well as the gender breakdown of Coeliac Australia membership (80% women; personal communication, January 12, 2018) and requests for CD serology testing per annum (two-thirds women; Anderson et al., 2013). The high levels of education reported in the sample (71.4% with undergraduate, post-graduate, or TAFE qualifications compared to 50.7% of the representative cohort with post-school qualifications) may, however, point to an additional bias and may have affected findings, as health literacy is likely to be linked to adherence (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Future research would therefore benefit from purposeful recruitment of groups currently under-represented in research (e.g., men, lower education, non-Caucasian

backgrounds, and patients who have chosen not to seek support from the Coeliac Society or other informal support group), as the relationships described here may differ.

A common limitation of GFD adherence research is the absence of a truly reliable and valid adherence measure that is feasible for use in large-scale research, and, in this way, this study is no different to previous work. It is well-established that while serological measures are reliable markers of intestinal damage at diagnosis, their use at follow-up is limited as they do not correlate well with the 'gold standard' dietitian-rated assessment or mucosal disease state, and produce frequent false negatives in known partially-adherent patients (Leffler et al., 2007; Vahedi et al., 2003). In contrast, the CDAT does correlate well with the 'gold standard' and was shown to be superior to serological tests (Leffler et al., 2009). While the addition of dietitian reports would clearly strengthen the current findings, in a study of >5500 people this would be financially and practically unfeasible. The findings can, however, be viewed with more confidence than studies that have utilised simple self-report measures of the frequency of gluten consumption, whether intentional or otherwise.

In the absence of existing measures to assess the maintenance constructs (except habit), novel questionnaires were used. Although the items and subscales performed well – that is, they were internally consistent, loaded on single components for each construct (except motivation), and correlated in the expected directions with adherence, PBC, and psychological distress – it was not possible to determine psychometric attributes such as construct or criterion validity, which represents a limitation and warrants further study. Nonetheless, they are a starting point and could also be adapted for use in other long-term behaviours. Further, the measure used to estimate the frequency of risk-taking when psychological resources and self-control are low may be of use in future GFD research as a proxy for unintentional gluten consumption.

This large study has demonstrated that the maintenance-relevant constructs of self-regulation, habit, maintenance motivation, psychological resources, social and environmental influences (Kwasnicka et al., 2016), and goal priority, conflict, and facilitation (Conner et al., 2016; Presseau et al., 2010) are useful for understanding how adherence to a GFD in CD happens. The

combination of rational, automatic, and emotional processes used here advances previous research. While not all previously unstudied in this field, their application within a coherent theoretical framework is an advantage and provides a lens through which decisions about appropriate mechanisms for behaviour change interventions can be made.

For example, in addition to prompting self-regulation and habit formation, the present results suggest that interventions may benefit from encouraging participants to gain insight into how lowered self-control in various psychological states may directly or indirectly impact their adherence. Strategy-wise, considering ways to minimise the frequency of these experiences and/or develop ways to cope when they do occur, might then mean that lapses in adherence are less likely. Regarding specific types of motivation, the findings also suggest that encouraging people with CD to focus on the longer-term benefits of following a GFD, and the satisfaction and enjoyment that comes from being well, may yield greater improvements in maintenance of the GFD over time than perceiving no choice and being motivated by merely wanting to avoid symptoms, feelings of guilt, or because somebody told you to. Finally, teaching skills to elicit and mobilise available social support from friends and family, and achieving balance within the less supportive weekend and work/study environments may be of benefit.

The care of patients with CD typically involves a medical specialist (gastroenterologist), general practitioner, and dietitian. Even with optimal medical care, a sizeable proportion of patients fail to achieve full symptom relief or mucosal disease remission (Rubio-Tapia et al., 2010). Together with findings relating to the importance of patient demographic and diseases characteristics in determining adherence (Halmos et al., 2017), psychological factors clearly play an important role and need to be recognised and more effectively addressed. This and other psychological studies therefore highlight an important place for a health and/or clinical psychologist as a member of the multi-disciplinary team and provide guidance on how change may be achieved – it is time to shift focus away from prediction and towards intervention design, implementation, and evaluation, so

1 that existing theoretical knowledge can be translated into effective and evidence-based healthcare
2 practice.

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